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## Family Experiences and Children With Autism Who Use Speech Generating Devices

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The University of Southern Mississippi

FAMILY EXPERIENCES AND CHILDREN WITH AUTISM  
WHO USE SPEECH GENERATING DEVICES

by

Rebecca Elizabeth Mullican

Abstract of a Dissertation  
Submitted to the Graduate School  
of The University of Southern Mississippi  
in Partial Fulfillment of the Requirements  
for the Degree of Doctor of Philosophy

May 2012

ABSTRACT

FAMILY EXPERIENCES AND CHILDREN WITH AUTISM  
WHO USE SPEECH GENERATING DEVICES

by Rebecca E. Mullican

May 2012

Semi-structured interviews were used to investigate family experiences with their children with autism who use Speech Generating Devices (SGDs). Six parents were interviewed on two separate occasions about their experiences with their child, ages three-eighteen. Interpretive Phenomenological Analysis (IPA) was used to analyze the interviews. Five super-ordinate themes emerged: (a) Complexity of speech generating devices as tools for communication, (b) Tension between structure and play, (c) Interplay between requesting and social interaction, (d) The fluctuating role of parent advocate, and (e) Building a diverse support network. These qualitative findings can be used to inform families and professionals working with children who have autism and use SGDs. Possible implications focus on topics surrounding family experiences with autism and SGDs.

Keywords: autism; speech generating devices; families; augmentative and alternative communication; qualitative, interpretive phenomenological analysis, AAC, SGD, IPA

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A Dissertation  
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May 2012

## DEDICATION

There are two groups of people I want to dedicate this dissertation to. The first is my family, who from early on, made me believe I could do anything, from being a singer to a judge. I am who I am because of the hope and belief you had in me. To my mom, who showed me what a strong woman could do, you are my hero! To my dad, I get my fight from you; I love and miss you. To my brothers and sister, thank you for your individual ways of supporting and encouraging me. To my number one fan and supporter, my husband, Bryce, with which I have seen all things are possible. Bryce, you are my dream catcher. You always believe in me and help my dreams come true. And just so you know, *this IS PHD!*

The second group I would like to dedicate this dissertation to is my family within special education. The two ladies who impacted and changed my life the most are Kathie DeJohn and Marsha Vance. I took a part of each of you with me into the classroom and will forever be grateful for all you taught me! Kathie, thank you for believing in me! Marsha, you have been by my side all these years and are still the first person I call.

I also dedicate this dissertation to “my children.” All of the children I have taught and worked with over the years, you have made me into the person I am today! “Because I knew you, I have been changed for good.” (Schwartz, 2003, track 18) This is for you and your families- may you never be satisfied with where you are or who you are, but continuously becoming a better you. I know you can do it! My ambition comes from wanting to see you become everything you are meant to be.

The Broadway show *Wicked* provided me a lot of confidence throughout my PhD program. I would like to leave you with an inspiring quote from the song *Defying Gravity* (Schwartz, 2003, track 11):

Something has changed within me, something is not the same. I'm through with playing by the rules of someone else's game. Too late for second-guessing, too late to go back to sleep, it's time to trust my instincts, close my eyes: and leap! It's time to try defying gravity...



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## CHAPTER I

### INTRODUCTION

An autism spectrum disorder is defined by impairments in communication, socialization, and restricted interests and hobbies (American Psychiatric Association, 2000). As the prevalence rate of children with Autism Spectrum Disorders (ASD) rapidly increases, so does the demand for research not only for causes of ASD, but also how to best serve the needs of this population. It is important to note that approximately 40% of children with ASDs do not have traditional oral language abilities. Because ASDs not only impair the individual's communication, but also his/her socialization and behavior, individuals who have autism and require communication support may have different needs and experiences than children with other disabilities.

Characteristics of autism affect the entire family and the way that family functions (Ferraioli & Harris, 2010). Parents of children with autism had higher levels of stress, anxiety, and depression than parents of children with other developmental delays (Gray, 2002). Parents and siblings of a child with autism also shared feelings of loneliness and withdrawal (Bilgin & Kucuk, 2010). Furthermore, family community outings are affected by a child with autism because of misunderstandings and the stigma attached to autism (Petalus, Hastings, Nash, Dowey, & Reilly, 2009; Tway, Connelly, & Novak, 2007). However, some families show signs of resilience and signs of positive effects of disability within the family such as increases in compassion, patience, and acceptance (Bayat, 2007; Petalus et al., 2009).

Advances in technology hold promise in helping address some of these areas of weakness. For example, assistive technology allows individuals with autism the potential to participate socially with others. More specifically, assistive technology allows individuals to communicate with others and decrease negative behaviors through communication (Mirenda, 1993). It is important to look at the entire family in regards to autism and speech generating devices to learn more about how they affect the family.

In 1989, the Technology-Related Assistance for Individuals with Disabilities Act gave states opportunities to create programs to meet the needs of individuals with disabilities through the use of assistive technology (Turnbull, 1989). In 1997, the Individuals with Education Improvement Act Amendments mandated assistive technology as a consideration for children with an Individualized Education Plan (IEP) (Yell, 2012). President Bush signed the Assistive Technology Act of 2004 which expanded access to technology for individuals with disabilities. There are devices that are specifically designed as assistive technology devices which have varying degrees of complexity. Low technology devices, such as the GoTalk, are not electronic (Glennen & DeCoste, 1997). High technology devices, such as those developed by Prentke Romich Company and Dynavox, are computerized, portable, use synthesized speech output (Mirenda, 2003) and have dynamic displays that change when touched (Glennen & DeCoste, 1997). Furthermore, in recent years, mainstream devices such as the iPad have been used for assistive purposes, including speech generation. Of these, those that allow individuals to communicate wants, needs,

thoughts, and have conversations by outputting speech are called Speech Generating Devices (SGDs).

Teaching children with ASD has presented many challenges to professionals and families alike. Of the many strategies, naturalistic teaching holds promise for teaching children with ASD to use assistive technology, as instruction occurs within the context of natural events and settings (Trembath, Balandin, Togher, & Stancliffe, 2009). Because of the functional use of everyday activities, naturalistic teaching is reinforcing and is an intervention strategy that, in conjunction with SGDs, improves communication for children affected by autism (Schepis, Reid, Behrmann, & Sutton, 1998) and may encourage generalization across environments. Naturalistic teaching paired with SGDs not only shows improvement in communication, but also in social interactions (Schepis et al., 1998). The use of naturalistic teaching in the home for activities such as storybook reading, sharing preschool experiences, and mealtimes also increases communication and allows more opportunities for engaging children with autism spectrum disorders (Koppenhaver, Erickson, & Skotko, 2001; Thunberg, Ahlsen, & Sandberg, 2007). Not only do SGDs allow children with autism to communicate, but research indicates that some children using SGDs actually increase speech or vocalizations (Olive et al., 2007; Ronski et al., 2010; Trembath et al., 2009). Children spoke words learned in intervention after the use of SGDs (Olive et al., 2007; Trembath et al., 2009).

Sources outside of professional research are also showing the possibilities of speech generating devices with individuals affected by autism. The documentary *Autism is a World* demonstrates how one individual is able to



express her thoughts and feelings with SGDs, whereas before using SGDs, her parents and doctors considered her mentally retarded (Wurzberg & Wurzberg, 2004). Through SGDs, her world has been opened and she is able to have more independence and control. SGDs and autism are also receiving attention from television shows, specifically Syfy channel. A show called *Alphas* shows a depiction of a lady with autism who appears to be mentally challenged until she uses a SGD to communicate (Penn & Gaviola, 2011).

As technology is becoming more readily available in homes and schools, more children with disabilities have opportunities to interact with and use technology in daily life. Technology has been used to assist children with autism in learning because it increases attention span and motivation (Lindstrand & Brodin, 2004). Specifically, the use of SGDs has an impact on individuals in a variety of aspects of daily living, such as social interaction, language and communication, literacy practices, learning, play, personal identity, and family life.

SGD use holds promise in several areas including communication, facilitation of learning, and literacy. Individuals with autism can communicate needs and wants when provided SGDs (Olive et al., 2007; Son, Sigafoos, O'Reilly, & Lancioni, 2006). An example of this is children with autism using SGDs within the preschool setting to select an activity or toy (Trembath et al., 2009). Children with autism use SGDs to facilitate learning. One way SGDs facilitate learning is assisting children with generalization skills (Sigafoos, O'Reilly, Ganz, Lancioni, & Schlosser, 2005; Trembath et al., 2009). Storybook reading within the home also allows children with autism spectrum disorder to

actively engage in reading activities through the utilization of SGDs (Koppenhaver et al., 2001).

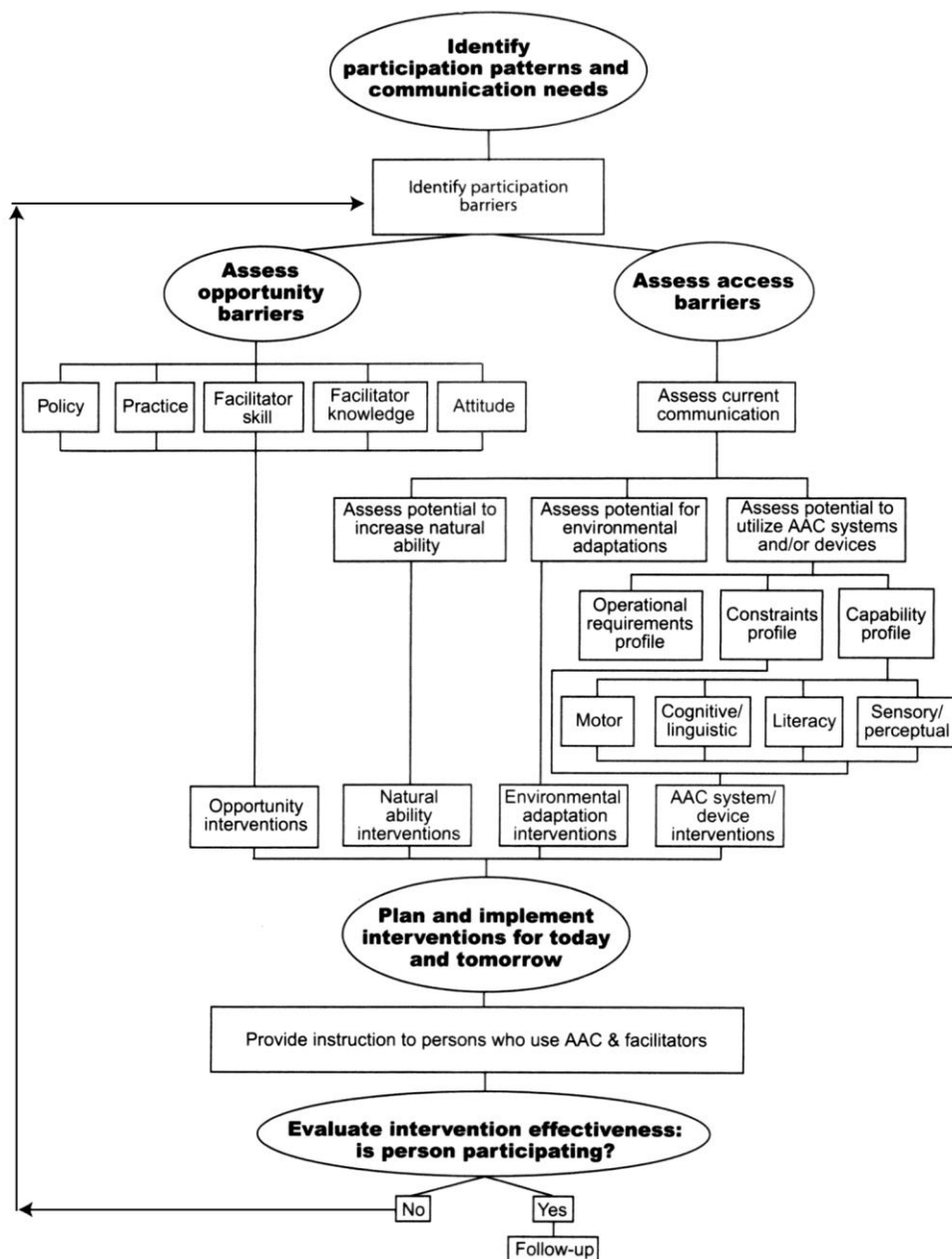
SGDs may also be used in a variety of ways to assist children with autism in socialization. Social interactions between the child and the parent or teachers improve when using SGDs (Schepis et al., 1998). Thunberg et al. (2007) notes parents changed behavioral patterns throughout the research study and moved closer to the child during interactions to assist the child with use of the SGD. Olive et al. (2007) notes children interacted more with teachers and paraprofessionals through SGDs to talk about things they want or need. Play is another aspect of social interactions that changes due to SGD use (Olive et al., 2007; Schepis et al, 1998). Finally, personal identity is shown through device use, as individuals with autism may have opportunities to express themselves in new ways (Marshall & Goldbart, 2008).

### Theoretical Framework

Social interactions motivate individuals to want to communicate (Mirenda, 1993). Although children with autism have this same desire, they may not have understanding of the social rules of communication (Beukelman & Mirenda, 2005). The Participation Model states there are no prerequisites to be capable of communicating (Hourcade, Pilotte, West, & Parette, 2004). Anyone that can benefit from augmentative and alternative communication should be introduced and allowed to determine what AAC may work best for them to meet their individual needs. As such, the model has allowed children who were not given opportunities before because of limited communication and unknown cognitive skills a chance to be evaluated for and use assistive technology. The

Participation Model states there are no prerequisites of communicating and use of a SGD to increase participation viable reason to utilize a SGD.

However, the participation model is a fairly new concept, with beginnings in the 1990's. The emergence of augmentative and alternative communication began in the 1950's and 1960's (Hourcade et al., 2004). Until the 1990's, children with disabilities had to meet criteria in order to be considered capable to use AAC (Hourcade et al., 2004). Children who did not function or appear to function within the set criteria were not considered for AAC. Prerequisites excluded many children with severe disabilities, including autism, from receiving AAC interventions. Mirenda describes this history “---since, if they could not communicate, there was no way they could tell us whether or not they liked the lives we designed for them. So, we assumed they did and continued to design them.” (Mirenda, 1993, p. 2).



*Figure 1. The Participation Model. The Participation Model was created to determine an individual's communication, barriers to communication, and how the use of AAC (augmentative and alternative communication) could be used to facilitate communication as well as the planning, implementation, and evaluation of the communication system. From *Augmentative and Alternative Communication: Supporting Children & Adults with Complex Communication Needs* (p. 137), by D. R. Beukelman & P. Mirenda, 2005, York, PA: Paul H. Brookes Publishing Co. Copyright 2005 by Paul H. Brookes Publishing Co.*

The Participation Model was developed to meet the needs of individuals requiring the use of Augmentative and Alternative Communication (AAC) through a systematic assessment process that leads to intervention design on an individual basis (Beukelman & Mirenda, 1998). The Participation Model lays the foundation that an individual's participation and inclusion is a viable reason for AAC use (Hourcade et al., 2004). Figure 1 shows the stages of the model. The model begins by asking if the person is able to communicate, how he/she communicates, and what communication is not working well. In this stage, it is important to not only determine barriers to communication, but to also look at previous forms of communication and the success of those uses (Glennan & Decoste, 1997). Previously used forms of communication also need to be assessed for determining if new strategies are needed to increase participation through communication techniques already in use (Beukelman & Mirenda, 1998). For example, if a child is using vocalizations to try and get the teacher's attention, but is unsuccessful, the child could learn to wait for the teacher to look and then call for her. If the child is unable to participate, the use of the Participation Model will next decide what communication barriers exist. Barriers occur through opportunity or through accessibility (Glennan & Decoste, 1997). Opportunity barriers include policy, practice, skills and knowledge of interventionist, and attitude. Communication pattern barriers are a type of opportunity barriers and occur if there are no opportunities for communication. An example of this is quiet lunches where students are unable to talk to each other. This would not be a good opportunity to incorporate AAC because students are not allowed to talk during this time. Accessibility barriers are barriers that disrupt communication due

to capabilities and needs of the individual (i.e. cognitive skills, past experiences with technology, and opinion) (Glennan & DeCoste, 1997). After barriers are realized, an intervention plan can be made and followed, with follow-up assessments.

Because the Participation Model is founded on the premise that there are no prerequisites to communicate, augmentative and alternative communication, namely speech generating devices, are a viable option for individuals with severe disabilities, including autism. Many of these individuals were not considered eligible before because it was difficult for them to show their cognitive ability without a way to communicate. Currently, the Participation Model allows any child that does not have an effective communication system to be evaluated for augmentative and alternative communication. The needs of individuals with severe disabilities, including autism, are able to be met because there are no set criteria stating individuals must show readiness skills to communicate or signs indicating they will be successful communicators. More individuals within the spectrum of autism are able to receive augmentative and alternative communication (Mirenda, 2003). Participation for individuals with autism has increased with the opportunities for more inclusion and social success (Beukelman & Mirenda, 2005).

### Problem Statement

There is a gap in the literature between initial uses of SGDs and ongoing uses of SGDs with children affected by autism. Many studies report that children affected by autism can benefit from the use of SGDs (Olive et al., 2007; Son et al., 2006; Sonnenmeier, McSheehan, & Jorgensen, 2005; Thunberg et al., 2007)

but there are little to no studies that report information regarding ongoing use of SGDs with this population. Families begin using technology, but 30% of those families stop using the technology within the first year (Scherer & Glueckauf, 2005). It is important to understand family experiences with SGDs and what factors may play a role in the ongoing use of SGDs. Smith et al. (2010) reported that there have been few studies revolving around the daily experiences of families with a child who has any type of disability. By talking to parents about daily experiences, the current study wishes to demystify the happenings from day to day in the families affected by autism and SGDs and understand how SGDs impact the families affected by autism in a variety of ways: social skills, behavior, communication and language, literacy, learning, and individuality.

Many research studies regard families as important in the decisions of augmentative and alternative communication (Bailey, Parette, Jr., Stoner, Angell, & Carroll, 2006; Rackensperger, Krezman, McNaughton, Williams, & D'Silva, 2005; Scherer & Glueckauf, 2005). However, there are few studies actually done in the homes or with families regarding AAC use (Sigafoos et al., 2004). While teachers, schools, and service agencies change, the one constant in a child's life is the family and in turn, the family's integration with SGD use may increase the chances of ongoing use of SGDs. The current study looks at how SGDs impact a variety of factors of family life through the child affected by autism. The current study also looks at what factors and forces are at play to assist families in the ongoing use of SGDs.

### Purpose of the Study

Technology abandonment occurs 33% of the time within the first year of use (Johnson, Inglebret, Jones, & Ray, 2006). The purpose of the current study is to take an in-depth investigation into the child and family dynamics impacting the use of SGDs. More specifically, exploring the daily lives of this group of families in order to learn what factors impact the use or abandonment of SGDs by children affected by autism. The technology itself does not determine how it is used, rather, it is the individuals using the technology that increase or decrease motivation to use. The current study explores how a group of families increase motivation to use SGDs and continue use for many purposes for the individual with autism, but mainly, communication.

The current study explores how the Participation Model has impacted a group of children with autism and their families in such aspects as communication, social interactions, and learning. The current study also explores how the Participation Model has impacted other areas of autism, such as the child's individuality. The current study allows exploration as to how the lives of families have been changed due to the Participation Model opening the opportunity for SGDs for these families who have a child affected by autism. The use of the Participation Model provides a structure for the inspection of families using speech generating devices with a child affected by autism because it provides an opportunity to see how some families have been impacted that may not have been given this possibility before. By using the framework of the Participation Model, those features that support or inhibit technology use, despite



clear skills deficits are explored. The current study seeks to understand factors that support technology use over time, despite the skills deficits of the child.

### Research Question

The current qualitative study investigates the impact of ongoing use of SGDs in areas of children's lives affected by autism. The current study also looks at the experiences of parents who have a child with autism who uses a speech generating device to communicate to determine factors surrounding the ongoing use of SGDs in families' daily lives and which factors may support ongoing use. The following research question frames the current study:

1. What are the lived experiences of families with children with autism who use SGDs?

### Limitations, Delimitations, and Assumptions

Limitations and delimitations allow researchers to understand what factors may have been influential in the current research study. In the current qualitative study, the aim of the study is not to generalize research findings to other similar groups, but to understand the experiences of a group of people who have a child with autism who uses a SGD. The following are ways that the current research study may be limited or delimited.

The current study relies on participants that volunteer to participate. Volunteer participants may be more likely to use the device with their child and be self-motivated to continue the use of the device in daily life. Many of the research studies in the area of autism, which use volunteers, generally have a large number of Caucasian, middle class families with little variability. This may be a limitation in the current study. This means there may be an

overrepresentation of this group and an underrepresentation of other groups.

Study results may not be generalized to other autism families due to the nature of the study.

The researcher delimits the number of participants in the study. By using a small number of participants, the researcher is able to examine each family affected by autism using SGDs more deeply. Another delimitation is interviewing only one parent from each family. Parents are asked to speak on behalf of their family; however, the experiences may be more closely associated to the family member being interviewed.

Assumptions about the study are parents continue to use SGDs with their child because the benefits outweigh the drawbacks. Parents have seen enough positive results, such as decreases in negative behavior, increases in communication and socialization, insights into personality and thoughts of their child, to continue to work with SGDs on a daily basis.

Assumptions about the factors surrounding device use include parents who utilize SGDs with their child on a daily basis for an ongoing period of time utilize a variety of technology within their own lives or receive high levels of support. Families who receive lots of support and training on device use feel less stressed about the device than parents who receive less support and training.

## Key Terms

*Assistive Technology (AT)* is defined as any equipment that allows an individual to participate more or be more independent. The variety of activities AT can assist range from bathroom, eating, communication, mobility, etc. and may be low or high technology (Glennen & DeCoste, 1997; Yell, 2012).

*Augmentative and Alternative Communication (AAC)* is defined as unaided and aided systems that allow an individual to communicate. Unaided systems involve use of the body, such as sign language or gestures. Aided systems require outside assistance and range from low technology to high technology systems.

*Autism Spectrum Disorder (ASD)* is defined by the DSM-IV-TR as disability that impairs communication, social interactions, and includes restricted interests and hobbies. (American Psychiatric Association, 2000)

*Children* are defined in the current study as individuals under the age of 21 that reside with his/her parents, foster parents, or grandparents.

*Family* in the current study is defined as a social group of parents or guardians and their children.

*High technology systems* are defined by the following characteristics: computerized, dynamic displays, and synthesized speech output. (American Speech-Language-Hearing Association, n.d.; Glennen & DeCoste, 1997)

*Individuality* is defined in the current study as how an individual shows his/her personality, interests, hobbies, thoughts, moods, etc. through the use of SGDs.

*Individualized Education Plan* is the legal document that states yearly goals for a child with a disability.

*Joint Attention* is “sharing attention and emotion” (Prizant, Wetherby, Rubin, Laurent, & Rydell, 2006) with another person (turn taking, having a conversation, etc.) and/or nonverbally (looking at each other, using gestures to communicate, etc.). Joint attention broadens with the child’s language and eventually encompasses concepts such as time and emotion in conversations with others (Adamson, Ronski, Bakeman, & Sevcik, 2010).

*Literacy* is defined as the components that make up the whole-to-part model which are: word identification, language comprehension, and print processing (Cunningham, 1993) and literacy for individuals using AAC also encompasses a means of self-expression and independence (Glennen & Decoste, 1997).

*Low technology systems* are defined as communication that is not electronic (Glennen & DeCoste, 1997). Low technology includes communication boards, picture exchange systems, simple speech generating devices, etc.

*Naturalistic teaching* is defined as teaching that occurs within the context of natural events or settings (Schepis et al., 1998).

*Navigation* is defined as important factors to the ongoing use of SGDs (i.e., how a family navigates their way through SGDs)

*Parent* is defined in the current study as a mother, father, or caregiver that lives in the home with the child and takes responsibility for the care of the child.

*Picture Exchange* is defined in the current study as a general term for a picture communication system that involves selecting the picture for

communication and taking it to another person to share wants, needs, or thoughts.

*Play* is defined as an exploration and learning of the world through sensory repetition which allows individuals to connect socially with adult assistance (Brodin, 2005).

*Social aspects* for the current study are pieces of social communication that allow two or more people to communicate with each other. Social aspects include: joint attention, verbal communication, nonverbal cues (such as eye gaze, gestures, and pointing), and interaction between communicators.

*Speech Generating Devices (SGD)* are high technology devices that provide speech output for individuals and have the following characteristics: portable, computerized, and speech output (Mirenda, 2003). Many also have a dynamic display screen that changes when touched (Glennen & DeCoste, 1997). In the current study, mainstream devices such as the ipod or ipad that are touch screens and output speech are not included as the main SGD the child uses.

### Summary

Autism research has become important as autism diagnoses are increasing. Because of the percent of children with autism who do not develop functional speech, there is a demand for research about how to support children who do not develop typical speech (Mirenda & Iacono, 2009). One of the interventions that may be considered for these children is Speech Generating Devices. Speech Generating Devices encompass a multi-sensory approach that assists children with autism in communicating (Trembath et al., 2009).

Because the Participation Model broadened the scope of augmentative and alternative communication for children with severe disabilities and autism, children with severe disabilities and autism are being allowed chances to receive new interventions that were not generally achievable before because of difficulty showing abilities or cognition. Now that speech generating devices have been determined useful interventions for children with autism (Schlosser & Blischak, 2001), it is also important to understand how this intervention impacts the child's emerging image and development; in addition, how the ongoing intervention impacts family life. The current study explores how a child's life and family is impacted by the use of speech generating devices.

## CHAPTER II

### REVIEW OF THE LITERATURE

It is widely believed that effective communication is essential to the human existence, that it is the foundation upon which human interaction is based, and is an instinctive reaction to human interaction (Mirenda, 1993). Children with autism experience many challenges including communication, socialization, behavior, and repetitive interests. Of these, the ability to communicate may present some of the biggest obstacles for these children (Schepis, Reid, Behrmann, and Sutton, 1998). An autism diagnosis is made for approximately one child in every one hundred and ten; and nearly forty percent of these children do not have functional speech (Center for Disease Control, n.d.).

Several laws have increased use of assistive technology use for individuals with disabilities. These include Public Law 99-457, Technology-Related Assistance for the Individuals with Disabilities Act, Individuals with Disabilities Education Improvement Act Amendments of 1997, and the Assistive Technology Act of 2004. These laws were enacted, at least in part, due to the emerging research showing success with AT (Glennan & DeCoste, 1997). Moreover, the 1997 amendments to IDEA added the requirement of assessment for assistive technology for all students receiving special education services, and the use of such technology to meet the goals and objectives of their individualized education plans (Yell, 2012).

One type of assistive technology being used is speech generating devices (SGDs). Speech Generating Devices (SGDs) have increased communication, inclusion, academics, friends, job employment, and helped decrease challenging

behaviors in individuals with severe disabilities (Mirenda, 1993). Schlosser and Blischak (2001) noted Speech Generating Devices (SGDs) are an appropriate communication intervention particularly for children with autism. In this population, educators and families have also seen positive changes in many areas due to SGD use including communication, social interactions, learning, individuality, play skills (Mirenda, 1993), and decreases in negative behaviors such as head banging, biting, screaming, meltdowns, or other maladaptive behaviors (Glennan & DeCoste, 1997). Speech generating devices may also increase speech or vocalizations among children with autism (Parsons & La Sorte, 1993).

Trembath et al., (2009) identified three factors which may facilitate the use of SGDs with children with autism. First, many children with autism are visual learners so the visual aspects of the SGD may facilitate learning. Second, the consistency and predictability SGDs offer are preferred characteristics by children with autism. Finally, SGDs allow children with autism to communicate with a variety of people. Advantages of high technology devices that use synthetic speech for children with autism are phrases and sentences are broken into words and the speech has consistent intonation (Parsons & La Sorte, 1993). Schlosser and Blischak's (2001) reported that monotone speech with limited affect may be preferable in SGDs for children with autism.



## Families and Autism

Families raising a child with autism cope on various levels. While some families are fairly satisfied with daily life (Bayat, 2007), other families report high levels of stress and difficulty with daily life (Hastings et al., 2005). The severity of autism also plays a role in family coping (Gray, 2002). The range of difficulties specific to children with autism (i.e. communication, behavior, and social interaction challenges) sets autism apart from other disabilities (Bilgin & Kucuk, 2010) and may impact the family in different ways. One example is social isolation of the family (Troy, Connelly, & Novak, 2007). The need for familial support was expressed, but is not always accessible for families (Margetts, Couteur, & Croom, 2006).

Parents raising a child with autism have higher levels of stress, depression, and anxiety than parents raising typically developing children (Smith et al., 2010). Parents also have concerns about finances and social support (Bilgin & Kucuk, 2010). Some parents perceive the school as a support for assisting their child and working on social and communication skills (Bilgin & Kucuk, 2010). The type and amount of support available to families of children with autism is reported to vary widely (Margetts et al., 2006).

Research also shows families report positive experiences resulting from raising a child with autism. Families felt values and or priorities had changed after the child received an autism diagnosis (King et al., 2006). Families became closer as a result of autism and were more compassionate, empathetic, caring, and resilient (Bayat, 2007). Families mentioned how the little things in life became that much more important and small successes were very important

(Bayat, 2007). A service provider that works with families affected by autism also indicated she had noticed families were healthier and tougher (King et al., 2006).

Mothers with adolescents affected by autism spend more time assisting their child than mothers with typically developing adolescents (Smith et al., 2010). A longitudinal study with families raising a child with autism showed that most mothers were still unable to work ten years after initial study began (Gray, 2002). In addition, the stress of mothers is related to the child's behavior (Hastings et al., 2005). Parental anxiety is also related to current daily life and planning and thinking about the future for the child (Bayat, 2007). So not only was life affected, but effects lasted over time because autism is a chronic disability (Bilgin & Kucuk, 2010).

Some of the literature describes the types of familial support on which parents of children with autism rely. Some families report little to no social support system (Margetts et al., 2006). When spouses rely only on each other, depression levels are reported to be related to the spouse's stress level (Hastings et al., 2005). Grandparents are a source of support for families and step in to assist both the grandchild and child (Margetts et al., 2006). Families who receive high levels of support from grandparents were also reported to be likely to receive higher levels of support from other sources.

### *Siblings of Individuals with Autism*

Siblings growing up with a brother or sister with autism express an array of experiences that include positive, negative, and neutral experiences. However, long-term effects of growing up with a sibling affected by autism are not fully understood at this time (Smith & Elder, 2010). Siblings' views are affected by

age, but not by gender (Benderix & Sivberg, 2007). Some of the aspects of a sibling's life affected by a brother or sister with autism are friendships, (Petalus et al., 2009), self-image (Smith & Elder, 2010), and behavior (Benderix & Sivberg, 2007). For example, violent behavior from the child with autism makes siblings feel unsafe and scared in their home (Benderix & Sivberg, 2007). Finally, family dynamics indicate family coping is related to sibling relationships (Rivers & Stoneman, 2003).

Siblings describe negative experiences with their brother or sister who has autism. Experiences that stick out to siblings are leaving public places or not being able to go into the community because of the unpredictability and or behavior of sibling (Petalus et al., 2009). The child with autism's erratic behavior often leaves the sibling afraid and some siblings withdraw or become lonely (Benderix & Sivberg, 2007). The sibling's social life is disrupted. However, siblings also feel sorry for their brother or sister with autism and take care of him or her regardless of the negative feelings they are feeling (Benderix & Sivberg, 2007).

Siblings also describe many positive experiences within home life. Some siblings state they are more caring or compassionate because of their sibling with autism (Bayat, 2007). Siblings accept the child with autism and sometimes engage in explanation to others about their sibling (Petalus et al., 2009). One girl stood up for her brother saying, "just because he did not talk did not mean he didn't have anything to say!" (Petalus et al., 2009). Positive sibling relationships do exist within families affected by autism.

Among sibling relationship experiences, there are also mixed and neutral experiences. Siblings develop a tolerance for their brother or sister (Petalus et al., 2009). Some siblings take part in a support group that allows them to express themselves. Siblings talk about strange behavior and desire changes within home life (Benderix & Sivberg, 2007). Siblings have different things that bother them about the brother or sister with autism and deal with a variety of issues in their own way (Smith & Elder, 2010).

Sibling relationships are also strained from time to time because of additional tension from people outside the home (Smith & Elder, 2010). There are tensions within the home as to the experiences a sibling describes, going from positive to negative events and feelings. In addition, siblings are constantly pushed and pulled to decide where to stand and whether to advocate, withdraw, etc. for their brother or sister (Petalus et al., 2009). These forces come from strangers and friends alike as siblings disclose their brother or sister with autism. Siblings have to make decisions about how to deal with all of the questions and whether to tell friends or not about their sibling with autism (Petalus et al., 2009). Siblings describe friendships as tricky because of their brother or sister with autism. Some friends are not accepting of the child with autism. This leads some siblings to keep their brother or sister with autism a secret from friends. Siblings have a variety of choices to make revolving around their brother or sister with autism.

Family life for families with a child affected by autism encompasses a variety of differences than typical families (Smith et al., 2010). Parents have high stress and psychological distress (Pottie & Ingram, 2008) and siblings struggle with

social relationships and a strained relationship with a brother or sister with autism (Benderix & Sivberg, 2007). However, within these challenges, some families report resilience, appreciation for the small victories, and overall strength and family bonding (Bayat, 2007).

### Learning Characteristics of Children with Autism

Autism encompasses an assortment of potential deficits in learning. Individuals with autism have also described different learning techniques that give them higher abilities to complete tasks that seem difficult for people without autism. Some of the skills that are difficult for children with autism are generalizing learned skills (Sigafoos et al., 2004) and retaining skills learned (Heimann, Nelson, Tjus, & Gillberg, 1995; Myers, 2007).

Because children with autism have difficulty generalizing skills learned from one setting to another or from one person to another, Sigafoos, O'Reilly et al. (2004) noted the importance of working on generalizing skills when teaching a child with autism by completing the task learned with a variety of people in a variety of settings. Despite these challenges, children with autism generalize across settings when using SGDs (Sigafoos, O'Reilly, Ganz, Lancioni, & Schlosser, 2005; Trembath et al., 2009).

Heimann et al. (1995) also noted another important skill that many individuals with autism have trouble with is retaining skills learned. When interventions stopped, some children with severe disabilities, including autism, lost skills they gained during intervention period (Heimann et al., 1995; Myers, 2007). Heimann et al. (1995) recommended for children with autism to continue educational interventions for the best outcomes. One way to facilitate retention of

skills is to ensure the skill is practiced or used regularly. By using SGDs on a regular basis, the child not only has a stable mode of communication, but also may retain what is learned. Technology has been known to allow some children with autism to engage in learning by increasing motivation (Lindstrand & Brodin, 2004). By using devices that are engaging and motivating, children with autism may retain communication gains made using SGDs.

Another way to increase motivation for children with autism using SGDs is to give the child access to many devices and allow the child to show his/her preference for a device (Son et al., 2006). Children with autism are able to show preferences between AAC systems (Sigafoos & Drasgow, 2001; Sigafoos et al., 2004; Son et al., 2006) and within SGD systems (Sigafoos et al., 2005). One study notes children with autism simply choose the SGD system that is easier to access (Sigafoos et al., 2009), while another study notes children go out of their way to select the device they like better (Sigafoos et al., 2005). Either way, considerations for what the child prefers should be taken into account because the SGD is meant to meet the needs of the child (Son et al., 2006).

Typically developing children naturally develop characteristics of learning (i.e. generalizing and skill maintenance) and take control over their lives by making choices without effort. However, children with autism are challenged by many of these skills. Because children with autism have difficulty generalizing skills learned to new settings, people, and materials, Sigafoos, O'Reilly et al. (2004) notes this is an important skill to work on with the use of SGDs. Retainment of skills is another challenge that children with autism face and using SGDs in many settings and with many people allows them to work on

maintaining skills learned (Heimann et al., 1995). Lastly, allowing children with autism to show preference in selection of SGDs gives them some control over their environment and motivates them (Son et al., 2006).

### Impact of Speech Generating Devices

Speech Generating Devices (SGDs) are being used with children affected by autism to assist communication (Sigafoos et al., 2005) and communication and language skills have improved for children with autism who use SGDs (Olive et al., 2007; Sigafoos et al., 2009). These children have also shown progress in learning, literacy, and language arts while using SGDs (Sonnenmeier et al., 2005). Children with autism have also shown gains in social interactions, as well as play and behavior. Parents of children using SGDs have also reported individuality, such as personality traits, becoming more well-defined through SGD utilization (Marshall & Goldbart, 2008).

Despite the complexity of both the purposes and forms of communication, research on communication in children with autism has primarily focused on fulfilling basic wants and needs (Chiang & Lin, 2008; Son et al., 2006). Furthermore, almost no studies have focused on the overall impact SGDs have on children with autism or their families (Sigafoos, O'Reilly et al., 2004). Most research available about autism and SGDs discuss social interactions, communication and language, and some aspects of learning (Olive et al., 2007; Sigafoos et al., 2005; Son et al., 2006). There are few studies that take place in the home with families that discuss social interactions, communication and language, and literacy (Sigafoos, O'Reilly et al., 2004; Thunberg et al., 2007).

Studies that have researched play and personal identity regarding families using SGDs and children with autism were not found.

Clarke, McConachie, Price, & Wood, (2001) researched use of Augmentative and Alternative Communication (AAC) with 23 children and young adults through interviews and focus groups. Most of the participants said AAC was not interesting. However, 17 participants noted that AAC helped them. Participants listed a variety of negative issues: day-to-day upkeep, feeling ostracized and low self-esteem. They mentioned being able to express their thoughts and feelings as a positive attribute of AAC. The participants enjoyed speech therapy, but felt that they would enjoy it more one-on-one where they would have time to communicate.

The research focuses about SGD use in the lives of children with autism mainly concentrate on basic communication (Choi O'Reilly, Sigafoos, & Lancioni, 2010; Schepis et al., 1998). Communication and initiations of social interaction improve with SGD use (Olive et al., 2007; Schepis et al., 1998). Literacy achievement is attainable for children with complex communication needs, whereas without the use of SGDs, literacy achievement would not be attainable because of participation barriers (Glennan & DeCoste, 1997). Use of SGDs within the home allows opportunities for interaction, play, and self-expression between parents and children with autism (Thunberg et al., 2007).

### *Communication and Language*

Providing children with disabilities with opportunities to communicate have been the foremost reason for SGD use within schools, therapies, and home (Beukelman & Mirenda, 2005; Mirenda & Iacono, 2009). SGD use increased



communication for children with autism and other related disabilities (Koppenhaver et al., 2001; Olive et al., 2007; Son et al., 2006; Thunberg et al., 2007). Within communication, children with autism are taught specific skills such as requesting, refusing, commenting, and aspects to resolve communication breakdowns. In conjunction with SGD use, speech or verbal approximations increased for some children (Olive et al., 2007; Trembath et al., 2009).

Requesting items wanted or needed has been an important part of research for children affected by autism using SGDs because of the importance given to being able to request items wanted (Olive et al., 2007; Son et al., 2006; Trembath et al., 2009). The use of SGDs has been shown to increase unprompted communication requests (Olive et al., 2007; Son et al., 2006). In 2008, Chiang and Lin's study found children with autism used language to request and comment more than for other uses (i.e., ask questions, reject, etc.). The majority of the studies included requesting opportunities and a request and exchange where the child manipulated the SGD to communicate.

Children using SGDs also become more able to refuse items and activities through use of SGDs. Choi et al. (2010) and Thunberg et al., (2007), examined the use of refusal by children with autism who used speech generating devices. Thunburg et al., (2007), reported most children with autism who participated in the study refused parent comments or items within the home environment during dinner and reading activities. Choi et al. (2010) researched children with autism and the ability to ask for an item, determine the item offered is incorrect, and then ask again for the item wanted. The children refused the unneeded items, but never refused the item needed for the activity. The children increased refusal

skills through the course of the study and were able to generalize the skill with two novel activities.

Beukelman and Mirenda (2005) state the use of commenting is an important stepping stone for more complex language needs and builds towards conversations. Studies reported commenting by children with autism or similar disabilities who used SGDs at home during dinner, reading activities, or talking about the preschool day. (Koppenhaver et al., 2001; Thunberg et al., 2007). Increases in commenting were noted on an individual basis during dinner, reading activities, and talking about the preschool day. Commenting also increased through SGD use during educational activities in school for a child participating in a case study (Sonnenmeier et al., 2005).

The ability to fix communication problems is another important aspect of communication, as it allows the child to learn persistence and to change communication when misunderstood. Studies reported children with autism could resolve communication problems (Choi et al., 2010; Sigafoos, Drasgow et al., 2004). Sigafoos, Drasgow et al., (2004), reported the two participants were able to resolve miscommunications proficiently through the use of SGD or communicative behaviors. One participant became solely dependent on the SGD by the end of the study. Choi and colleagues (2010) conducted a study that required children to request a missing item, reject the item offered if it was not the item needed, and re-request the item needed. The children were able to continue resolving miscommunications throughout the study.

Another benefit of SGDs may be to actually increase speech or vocalizations for children with autism (Millar, Light, & Schlosser, 2006; Ronski et

al., 2010). Speech generating devices provide children with immediate communication opportunities and do not hinder speech abilities (Ronski et al., 2010). Some children with autism began to use to natural speech during the implementation of SGDs with child-centered play in natural school environments (Olive et al., 2007; Trembath et al., 2009). Additionally, some children with disabilities, participating in a storybook reading intervention with SGDs increased speech (Binger, Kent-Walsh, Berens, Del Campo, & Rivera, 2008). Other findings indicate that children supported by AAC or SGDs were more successful with speech after parent-coached intervention and generalized speech into new settings (Adamson et al., 2010; Ronski et al., 2010).

Children with autism who use a SGD attain new communication skills. Children with autism who utilize SGDs improve their requesting and refusing ability, enabling them to let others know if they do or do not want an item or activity offered (Choi et al., 2010; Thunberg et al., 2007). Children with autism also learn to comment on actions through SGD use (Koppenhaver et al., 2001; Sonnemeier et al., 2005), which is an important aspect of conversational skills (Prizant et al., 2006). Another skill that children with autism learn through the incorporation of SGDs is how to repair a communication breakdown to let someone know they have been misunderstood. Finally, research indicates that use of SGDs assist children with autism in gaining speech. Generalization is a challenge for children with autism (Sigafoos, O'Reilly et al., 2004), but if the uses of these new communication skills are generalized into the home environment, allowing the child opportunities to practice skills will improve the child's maintenance of skills (Heimann et al., 1995).

### *Literacy Attainment*

Jewitt (2010) states the definition of literacy stretches far beyond the typical reading and language aspects into social interactions, nonverbal communication, and kinesiology. For children with disabilities, literacy is described and broken down into achievable pieces such as word identification, language comprehension, and print processing with the goal of independent reading with understanding (Cunningham, 1993) and is a means of self-expression and independence for children using AAC (Glennen & DeCoste, 1997). Literacy development is crucial to progress for children with disabilities (Sturm, 2003). Typically developing children begin early engaging in the four modes of literacy: listening, talking, reading, and writing (Hetzroni, 2004). In addition, it is increasingly important to include visual representation in the conception of literacy (Jewitt & Kress, 2003). Children with communication disabilities, including autism, have access and opportunity barriers that do not allow them to engage fully in literacy activities. However, with the use of the Participation Model and Assistive Technology, children with communication disabilities can actively engage in literacy experiences and attainment of literacy skills (Hetzroni, 2004). While parents of typical children listed literacy as a priority, parents of children with severe speech and physical disabilities listed health, development, and self-care skills as priorities (Light & Kelford Smith, 1993). This suggests that parents with children who have severe disabilities (including autism) have concerns that become more of a priority than literacy. In addition, children affected by autism who use SGDs may be at further risk of

receiving less instruction in literacy because of the high demand for interventions across all educational areas (Beukelman & Mirenda, 2005).

Emergent literacy practices have been used with children who have Autism Spectrum Disorder (ASD). Storybooks have been used to engage children with ASDs in various language skills such as listening, answering questions, and commenting (Koppenhaver et al., 2001; Thunberg et al., 2007). Children with autism generally have trouble with theory of mind which in turn makes some aspects of language comprehension in literacy difficult for them, such as interpretation, prediction, and character analysis of the story and phonetic difficulties like sounding out nonsense words (Mirenda & Iacono, 2009).

Technology has increased literacy and language skills among many children with autism because children are highly engaged and motivated by the use of technology. Children with autism made the most significant gains throughout the use of a literacy computer program (Heimann et al., 1995). Children with autism increased requesting help and expressive language, program enjoyment, and attention to task. The children were more self-confident and able to work on their own without requiring teacher assistance.

Researchers stated that children using AAC to communicate were less likely to engage in literacy practices because of fewer opportunities to respond and engage in literacy with parents (Light, Binger, & Kelford Smith, 1994). Researchers noted AAC users also skipped their turns in conversations because of the difficulty of conversation flow (Myers, 2007). However, educational assistants who received training to assist children with disabilities using SGDs during story time increased child responses throughout the intervention (Binger,

Kent-Walsh, Ewing, & Taylor, 2010). Children with disabilities who participated in an intensive literacy program made literacy and writing gains during the intervention and some of the children maintained progress after implementation (Myers, 2007). Other children also made literacy progress through structured learning environments or school (Sonnenmeier et al., 2005; Soto, Yu, & Henneberry, 2007).

Descriptions of literacy attainment, learning process, and best practices for children using SGDs is limited in the research. For children with autism who have severe communication challenges, literacy may not be a top priority at home or school (Beukelman & Mirenda, 2005). However, use of technology may aid increased literacy skills for these children. Increased literacy skills (i.e. sentence construction) may also facilitate more complex use of SGDs, with better, more detailed communicative exchanges and self-expression.

### *Social Interactions*

Social interactions are the components of social communication that allow children with autism to communicate with other people. Social aspects include: joint attention, verbal communication, nonverbal cues (such as eye gaze, gestures, and pointing), and interaction between communicators. Like all children, those with disabilities have opportunities for social interactions among familiar and unfamiliar interaction partners (Valiquette, Sutton, & Ska, 2010).

Social interactions occur with familiar and unfamiliar partners. Familiar interaction partners include family, school, and peers, while unfamiliar interaction partners are those with whom the child does not interact with on a regular basis. Success with familiar partners came easier than with unfamiliar partners. SGDs

can increase interactions, as children with autism initiated interactions with teachers and teacher assistants more after devices were introduced (Schepis et al., 1998). The use of SGDs within the family or school increased social interactions and decreased maladaptive social skills (Sigafoos et al., 2009). Parents commented that SGD use within the home brought them physically closer to their child for better understanding and use of device (Thunberg et al., 2007). Parents of children with autism value technology, specifically, computer learning, as a way to bridge the social gap between themselves and their child (Heimann et al., 1995).

Parents describe a special bond with their child with a disability (Goldbart & Marshall, 2004; Marshall & Goldbart, 2008). This bond includes a deep understanding of the child and his wants, needs, thoughts, and desires. It also allows parents to have a deep understanding of their child, but also clouds their vision at times and may not allow them to detach from the nonverbal ways their child communicates with them. Parents may become used to interpreting gestures, vocalizations, and behavior as communication instead of relying on the child to use the SGD as the facilitator. This special bond sometimes made it difficult to focus on SGD use because of the nonverbal understanding between parent and child. For example, one parent reported her interactions and conversations with her child were different. His lack of speech changed her interactions by engaging him in fewer conversations (Marshall & Goldbart, 2008).

So, while there was success within familiar partners, there were mixed experiences with unfamiliar partners. Some parents were satisfied with their child's interactions with unfamiliar partners. Families commented on the myriad

of responses from unfamiliar individuals being overly interested, missing the point of the interaction for the child, or being helpful. Some parents discussed the frustrations with unfamiliar partners and how it added extra work to coax unfamiliar people to talk to their child (Marshall & Goldbart, 2008).

Social interactions were strongly linked to other areas of development, such as communication and play skills. A resurfacing theme families talked about was how interrelated communication was with social success. Some parents talked about how their child's lack of communication held them back from making friends. Play and social skills were also linked with communication. Children with disabilities who showed higher levels of joint attention were more likely to use SGDs at a higher rate during play sessions than children with disabilities using speech or pictures to communicate (Adamson et al., 2010).

### *Behavior*

Behavior is an expression of feelings, thoughts, and desires and is strongly linked to communication (Murray-Slutsky & Paris, 2005). Behavior encompasses anything a person does to communicate without using speech. People with limited or no speech use behavior to communicate what they are thinking and feeling. SGD use positively impacts the child's behavior patterns and allows the child to communicate through more socially appropriate and understandable methods instead of using negative behaviors for this purpose. Chiang (2008) reported children with autism who did not use speech generating devices used challenging behavior to request or refuse. Negative behaviors have been shown to decrease with the use of augmentative and alternative communication (Choi et al., 2010). Behavior patterns positively changed and



increased parent-child interactions during an SGD intervention (Thunberg et al., 2007). The children in the study received more parental attention during the use of SGDs because the parent moved closer to see and hear what the child said.

Behaviors also refer to nonverbal communication, such as pointing and gesturing. SGDs may affect other communicative behaviors, such as these. Children with autism or Rett's syndrome did not use nonverbal behavior when engaging in SGD use (Koppenhaver et al., 2001; Sigafoos & Drasgow, 2001). Instead, students replaced behavior communications with use of the SGD (Sigafoos, Drasgow et al., 2004). However, some children utilizing SGDs continue to use additional communicative behaviors (Schepis et al., 1998).

How SGDs affect behavior patterns with children affected by autism at home are not well-documented, but behavior challenges are among the stressors for families living with autism (Hastings et al., 2005). There is a relationship between challenging behavior and expressive communication skills (Chiang, 2008; Murphy et al., 2005). Implementing SGDs may be difficult with children who exhibit challenging behaviors (Sigafoos, O'Reilly et al., 2004). However, challenging behaviors decrease within SGD implementation (Choi et al., 2010) due to the integration of expressive communication (Chiang, 2008). In addition, SGDs not only decrease challenging behaviors, but also increase positive behaviors (Glennan & DeCoste, 1997).

The use of SGDs with children who have autism is important because it affects behavior patterns and children with autism have behavior challenges. Choi (2008) states children with autism use negative behaviors to communicate. Behaviors are closely linked with expressive communication (Beukelman &

Mirenda, 2005). Many children that do not have a way to communicate use challenging behavior to communicate which can takes years to replace with appropriate communication and social interactions (Glennan & DeCoste, 1997). The family's use of SGDs for children with autism affects many development areas for the child with autism. Because behavior, communication, and social interaction are all closely related, these areas are all affected by the use of SGDs.

### *Play*

Brodin's (2005) definition of play combines Piaget, Winnicot, and Vygotsky's thoughts and ideas about play. Play is an exploration and learning of the world through sensory repetition which allows individuals to connect socially with adult assistance. Children with autism show deficits in play and tend to get stuck in repetitive play routines and specific interests (CDC, n.d.; American Psychiatric Association, 2000). Play routines and imaginative play skills generally need to be taught to children affected by autism (Lantz, Nelson, & Loftin, 2004). In Brodin's (2005) study, a parent shares her thoughts on play:

To speak of play when it concerns a profoundly disabled child I do not consider right. For me it's a question of physical response from a small autistic child. It's a question of training all the senses that are sleeping. (p. 643)

A parent in Brodin's (2005) study mentions how the senses of children affected by autism need to be awakened in order to teach them how to play. This facilitation of play with a child with disabilities is a vital key to success and parents are the primary facilitators of teaching play. The majority of parent-child

interactions take place during play because play is such an important aspect of childhood (Lane & Mistrett, 1996).

Types of play researched for children with autism using SGDs include peer-mediated play, naturalistic play, and technology play. Peer-mediated play, naturalistic play, and technology play allowed children to increase communication and play. Children with autism naturally played with speech on their personal device as a way of exploration, learning, and speech recognition. Many parents deemed it important to allow their child to explore and talk on the device without expected communicative intent (McNaughton et al., 2008).

Naturalistic teaching combines everyday events, routines, and settings with child-centered play to teach language (Schepis et al., 1998). Naturalistic teaching and peer-mediated plays are used as intervention tools to increase communication skills for children with autism using SGDs. Both of these interventions follow the lead of the child with autism and play is based on what the child with autism likes or wants to play with. In naturalistic teaching, an adult facilitates communication and play with the child with autism, while peer-mediated play is facilitated by a peer. An example of these interventions is a child going between reading and Lego play with either an adult or peer following him and trying to engage him in the activities by talking, sharing items, and interacting. Naturalistic teaching is an important communication intervention tool for children with autism (Koegel, 1995). Naturalistic teaching paired with SGD use increases communication requests and spontaneous requests during play activities for children affected by autism (Olive et al., 2007; Schepis et al., 1998). Peer-mediated play is the use of same age peers, playing with the child, trying to

elicit interaction and shared play. Peer-mediated play improves children with autism's communication with peers during play activities (Trembath et al., 2009).

Children with disabilities take more time to learn skills such as play. Therefore, because play is so vital to development, children with disabilities need strong incentives that hold their attention and allow them to learn through play (Brodin & Lindstrand, 2000). Technology may be one of those strong incentives for children with autism because they engage and self-motivate through technology use (Heimann et al., 1995). Parents of children affected by autism state that computer use could also serve as a communication and social bridge between themselves and their child (Lindstrand & Brodin, 2004). Computer software that gains attention and motivates children with disabilities also allows parents to be able to play and connect with their child during the computer program.

Many parents and adult device users state both device exploration and play was helpful for the device user (McNaughton et al., 2008; Rackensperger et al., 2005). One parent suggests incorporating things the child likes on the device and using the device as a game by modeling for the child (McNaughton et al., 2008). Another parent states modeling with stuffed animals motivates his daughter to talk with the device (McNaughton et al., 2008). Exploring and playing with technology allows the child to learn, make connections, and play with words all at once. Device exploration can be explained as similar to how a toddler learns to talk through play with words. Babies first begin by using gestures, vocalizations and nonverbal communication which is followed by vocalizations that turn into words around eighteen and twenty-four months (Mirenda & Iacono,

2009). So for example, toddlers may have a small sound *ba* which later turns into the word *baba* representing *bottle*. Most devices do not have words broken into sounds, so children using SGDs must explore and learn whole words. Therefore, play on the device is not only play through repetition with a sensory object, such as Piaget stated, but also language development through exploration (Piaget, 1962).

Play is an important part of the parental bond with a child (Lane & Mistrett, 1996). However, in children with autism this bond through play becomes harder to achieve (Lantz et al., 2005) and parents need motivating things to utilize in play, such as technology (Lindstrand & Brodin, 2004). Play through the use of SGDs also facilitates language development and exploration (Prizant et al., 2006). Play is an integral part of childhood (Lane & Mistrett, 1996) and is not only fun, but also teaches children how to learn, make connections, interact with others, and explore their world. The use of SGDs in play for children with autism affects learning, interactions, and exploration of the child's world through language which are vital parts of development (Brodin, 2005).

### *Individuality*

Another area of importance for all individuals, including those with autism, is how the individual shows his/her personality, interests, hobbies, thoughts, moods, etc. There is a lack of research identifying how children with autism use SGDs to show their individuality. Parents of children with disabilities described SGD use as increasing their child's self-image (McNaughton et al., 2008). SGD use also allowed children to begin to show their personalities (Marshall &

Goldbart, 2008). Lastly, children using SGDs have a sense of pride and ownership over their device (McNaughton et al., 2008).

Individuals with disabilities describe the impact of the device on their self-image in positive and negative ways (Clarke et al., 2001). Some felt that it allowed them to say what was on their mind, while others said it made them feel awkward and different. However, parents described their child as having higher self-esteem because of device use (Goldbart & Marshall, 2004).

Children with disabilities talked about how SGDs allowed them to show their personality through language use, word choice, and more control over social situations. Some of the reasons they liked their device were being able to show who they are, have a voice, make choices known, take turns in conversations, and be included (Newton et al., 2006). Some children mentioned feeling good about being able to change their minds after they had spoken and be understood. Being able to tell jokes and express themselves with similar vocabulary as peers was another reason children liked their devices. Parents reported SGD use allowed their child to show personality traits through expression of emotions or how they handled communication breakdowns (Marshall & Goldbart, 2008). One parent reported her child becomes a hot head if not understood, while another parent talked about her child's persistence showed her personality.

Parents said allowing their child to play and explore the device helped the child feel the device belonged to them and gave them a sense of pride and control (McNaughton et al., 2008). Adults using devices even talked about the importance of being able to customize their device in the way that fits best and

helps show their individuality (Rackensberger et al., 2005). Adults also decided how to communicate with others, whether they wanted to pre-program sentences for certain situations or how to set the device up to best meet their needs according to their personality and what works best individually.

Communication allows children with disabilities, including autism to share thoughts and ideas, show personality, and have control over aspects of their life (Goldbart & Marshall, 2004). Parents reported that communication allowed their child to begin to have conversations and increased their self confidence (McNaughton et al., 2008). As a child is able to communicate, the identity of that child becomes more apparent (Goldbart & Marshall, 2004). Researchers stated SGD's assisted individuals in showing personality, explaining thoughts, and speaking their minds (Clarke et al., 2001).

In conclusion, the use of SGD's impacts children with disabilities, including autism developmentally as well as in family life. Through the use of SGD's, children with ASD make educational strides (Koppenhaver et al., 2001) and well as social strides (Olive et al., 2007). Children with disabilities show their personality (Goldbart & Marshall, 2004) and grow developmentally through play (McNaughton et al., 2008) and literacy (Myers, 2007) utilizing SGD's. Additionally, using SGD's allows children with autism to refuse things they do not want and tell people what they do want without the use of negative behaviors (i.e. biting, hitting, screaming) (Choi et al., 2010). Overall, being able to communicate allows children with autism to gain more independence and control over their lives (Brotherson, Cook, & Parette, 1996).

### Family Factors Influencing Use of Speech Generating Devices

Because of the reports of high levels of stress in families raising a child with autism (Pottie & Ingram, 2008), it is important to understand the experiences that help determine whether families will use SGDs within the home. Parental perceptions about SGDs and communication needs are important factors in the use of SGDs (Granlund, Bjork-Akesson, Wilder, & Ylven, 2008) because parents who think their child doesn't have a communication system are more motivated to use SGDs. The involvement of families not only in evaluations, but also in implementation and collaboration is another factor that can decrease technology abandonment (Brotherson et al., 1996; Ogletree, 2007). After evaluation, parents find themselves contributing a lot of effort in daily device use which adds extra stress to parents (Goldbart & Marshall, 2004). Parents do see improvement in their child as a result of SGD use (Binger et al., 2008), but are still discouraged by the things their child still cannot do (McNaughton et al., 2008).

Several studies have examined parents' perceptions of the usefulness and utility of speech generating devices. In one study, parents raising a child with disabilities who had limited or no speech stated how important communication was and how communication was closely related to social success (Goldbart & Marshall, 2004). Valiquette et al. (2010) reports children use a variety of forms of communication in addition to using SGDs in home settings. Other studies show parents are satisfied with their communication utilizing SGDs with their child within the home setting, but some remain unsatisfied with communication outside of the home in unfamiliar settings or with unfamiliar people (McNaughton et al.,



2008; Valiquette et al., 2010). Difficulty understanding what their child was communicating to them has been reported (Marshall & Goldbart, 2008).

The child's functioning within a family is the most important predictor of the child's overall development and general level of functioning. Understanding these factors can facilitate assistive technology teams when evaluating assistive technology needs (Bronfenbrenner, 1999). For children using assistive technology to communicate, the family members are the most important communication partners with family involvement in the process of SGDs, cited as critical to the process throughout research (Brotherson et al., 1996; Granlund et al., 2008; Hetzroni, 2002). Family involvement has also been identified as a way to decrease technology abandonment (Bailey et al., 2006). Families come to SGD evaluations with expectations for their child, which include increased independence, communication, and generalization into a variety of settings (Bailey et al., 2006). Other expected benefits from SGD use include increased: self-esteem, understanding by unfamiliar people (Newton et al., 2006), learning, and social interactions (Lindstrand & Brodin, 2004). Collaboration with the family ensures SGD use within home life, such as physical aspects of the home, routines, and family needs and wants are considered (Brotherson et al., 1996). McNaughton et al. (2008) suggest families who feel comfortable with mainstream technology before SGD use were possibly more inclined to be successful incorporating SGDs into family life. However, each family has different needs and different levels of involvement in the SGD process (Angelo, Jones, & Kokosko, 1995).

For successful family incorporation of SGDs into daily family routines, families need to devote time to learning and incorporating SGDs (Parette & Angelo, 1996). It has been suggested that families include extra time to complete daily routines and allow the SGD user to communicate during those daily routines. Both learning how to use the device and then incorporating its use into routines can be difficult and time-consuming (McNaughton et al., 2008). Parents express frustration with SGDs and the level of support received (Goldbart & Marshall, 2004).

When parents are required to take on the roles of managing the device and teaching the child to use it within the home, it adds stress and effort to parents, which can increase negative feelings (Goldbart & Marshall, 2004). Not only do parents engage in the role of advocating for their child, they also are the experts on their child and on SGD use by their child (Marshall & Goldbart, 2008; Valiquette et al., 2010). Parents report a lack of support in managing the device and teaching the child to use it within the home, and many parents take on the role of teacher as well as programmer. These parents support themselves in learning about SGDs and state how they feel lonely in this process (Marshall & Goldbart, 2008).

Within the use of SGDs, families shared concerns about many areas of development such as communication, social interactions, and cognitive development. One concern parents had was the lack of cognitive skills, such as understanding abstract ideas like time passage (i.e. what did you do yesterday? What are you going to do tomorrow?) (Lindstrand & Brodin, 2004). Another major concern among families was peer relationships. A parent stated how the lack of

communication stopped her child from having friends (Goldbart & Marshall, 2004). Peers would not wait while the device loaded so many parents felt their child became left out (McNaughton et al., 2008). One child participated in conversations with his brother's friends because they were familiar with him and the SGD (McNaughton et al., 2008). However, this situation was few and far between.

On the other hand, the use of SGDs within the family allowed the family many benefits. Families felt that their child was better understood after incorporating SGDs into their home life (Binger et al., 2008; Ronski et al., 2010). The use of SGDs also allowed families to achieve small victories, such as the child sharing original wants and thoughts (McNaughton et al., 2008). Families were able to see personalities and self-confidence in their children that were not as clear before (Goldbart & Marshall, 2004; Lindstrand & Brodin, 2004; Marshall & Goldbart, 2008).

### *Technology Use in the Home*

Assistive technology within the home can increase independence and self-esteem for a child with disabilities (Brotherson et al., 1996). The more technology is incorporated into daily life, the more likely parents feel comfortable with SGDs while parents who do not incorporate technology into daily lives are less confident with device use (McNaughton et al., 2008). Technology use, specifically SGD use, is not only reliant on the equipment itself, but also the reliability and ease of technical aspects (i.e. programming device) (Hodge, 2007).

Parental perceptions and past experiences, such as computer experiences, family routines, and perceptions with technology are important

predictors of technology use within the home (Lindstrand & Brodin, 2004). In addition, families' interest and experiences with technology also play a role in their perceptions of the possibility of technology assisting their child with a severe disability in daily life (Lindstrand & Brodin, 2004). Further, children with autism enjoy computer and technology use and are able to learn while using technology (Heimann et al., 1995). This, in turn, makes parents of children with autism value computer use with their child because it allowed their child to socially and playfully interact within the family (Lindstrand & Brodin, 2004).

Assistive technology does not always provide the exact features that are needed and wanted. Important features for laptop use for children with disabilities are related to portability, parent, teacher ability, and training (Priest & May, 2001). Some of the less important factors were upgrading, funding, technical features, and child's independence with laptop. However, for families incorporating SGDs in home life, portability and weight are also some of the main concerns among families using SGDs (Newton et al., 2006; Valiquette et al., 2010). Another important aspect of technology use in the home is the ease of reliability and working with technical features (i.e. programming) because these factors determine not only long-term use, but percent of daily use (Hodge, 2007).

Hodge (2007) notes that SGD potential is not being met because of many barriers such as the slowness of the device to respond and how devices do not let SGD users keep up in conversations. In addition, family factors like previous experiences and perceptions are also important to SGD use. In addition, overall comfort within technology is important to determine family use of SGDs.

## Training and Support Needs

Within the research about SGDs and autism spectrum disorders, five studies were found that implemented parent training strategies (Adamson et al., 2010; Binger et al., 2010; Ronski et al., 2010; Sigafoos, O'Reilly et al., 2004; Thunberg et al., 2007). Upon implementation, the communication of the child increased. Parents who received device trainings during research do not have personal SGDs for their child. However, adult device users and parents who have a personal SGD for their child are not receiving everyday device training for home implementation (O'Keefe, Kozak, & Schuller, 2007). Children with autism need to be able to communicate within the home setting (Sigafoos, O'Reilly et al. 2004). Parent training allows this to be more attainable.

Structured methods were used to teach parents interventions with SGDs and children with disabilities. Interventions were similar with regard to specific instructions of how to implement the teaching strategy with the child, but varied in processes of how to do this. Some interventions allowed parents to slowly take over the interventionist role (Adamson et al., 2010; Ronski et al., 2010), while other interventions taught parents a strategy within a few hours (Koppenhaver et al., 2001; Thunberg et al., 2007). Through trainings, parents felt accomplished and saw communication results (Binger et al., 2008).

There is a need for device training for families (Thunberg et al., 2007). Families acknowledged programming SGDs and trainings as stressful (Bailey et al., 2006). Some families have access to trainings, while other families seek out trainings on their own (Marshall & Goldbart, 2008). Interventions that taught parents how to instruct their child's use of a SGD may lead to not only increased

communication, but also generalization outside of the interventions (Adamson et al., 2010). SLPs perceptions of AAC technology abandonment found that approximately 70% of technology abandonment was due to lack of understanding or training on the device (Johnson et al., 2006). Other factors SLPs listed that were important to AAC on-going use for families are support, device fit with the family, perceptions, and device traits.

### *Speech Generating Devices and Professional Support*

The amount of professional support needed to achieve successful communication with SGDs varies child to child. However, learning how to use a device can take up to two years (Rackensperger et al., 2005). In addition, there are software needs (O'Keefe et al., 2007) and device breakdowns that also require support from AAC professionals (Shepherd, Campbell, Renzoni, & Sloan, 2009). During the evaluation process, families were not aware of the amount of work that takes place for a child to communicate successfully using an SGD (McNaughton et al., 2008). Understanding the effort needed to increase likelihood of success for children was an important factor for professionals to discuss with families (Bailey et al., 2006).

Families should be involved in the decision-making process when selecting an SGD (Parette, Meadon, Doubet, & Hess, 2010). By involving the family, parents are able to share input and increase chances of receiving a device that works for the child and the family. Furthermore, parents of kids with disabilities have a special bond with their child and have a deep understanding of the child and family's needs (Brotherson et al., 1996). Family routines should also be considered when evaluating a child for assistive technology to allow

further chances for successful integration (Brotherson et al., 1996; Grandlund et al., 2008).

Stephenson and Dowrick (2005) listed collaboration between schools, Speech Language Pathologists (SLPs), and families as one of the most important ways to facilitate SGD use. Parental involvement was also an important part of collaboration. SGD goals should consider family needs as goals that were not important to the family added stress and challenged families (Granlund et al., 2008). SGD goals should be a shared commitment between collaborators (Angelo et al., 1995).

Parents expected to receive support for SGDs from the SLPs more than any other school or private personnel. Professional support was important to assist parents in further understanding their child's communication and how to facilitate communication, as well as communication breakdowns (Hetzroni, 2002). Professional support was also needed for understanding the technical aspects of the device (Stephenson & Dowrick, 2005). The amount of support received varied from family to family (McNaughton et al, 2008). Some adult device users felt that Speech Language Pathologists held them back, didn't listen to their opinions, or were not very helpful (Rackensperger et al., 2005). Children with disabilities using devices talk about not feeling like there is time to communicate with the device in speech therapy. On the other hand, some parents talked about how lucky they were that they had great support from the SLPs and how helpful speech therapy was (Goldbart & Marshall, 2004). Children with disabilities using devices felt they received understanding from the SLP, felt relaxed and able to take a speaking turn in speech therapy (Clarke et al., 2001).

From yet another perspective, some parents determined that professionals working with SGDs were in a specialty field and there was a lack of qualified professionals (Rackensperger et al., 2005). Many parents understood the caseloads of SLPs did not allow enough time to learn a device and adequately teach it to their child (McNaughton et al., 2008).

Without the needed support, families had a variety of ways to cope. For some families, they supported and learned from each other and other device users (Rackensperger et al., 2005). Other families mentioned being on their own to figure out the SGD and how to incorporate it within their child and family life (Marshall & Goldbart, 2008). Parents seemed to either become aggressive to get their child's needs met or became distant from the process. For various reasons, some families were unable to continue device use.

Over time, families who perceived they did not receive enough support and AAC intervention disrupted daily life were less likely to implement the intervention and more likely that the AAC intervention was perceived as burdensome and stressful (Granlund et. al., 2008). Approximately 25% of technology abandonment was related to lack of support (Johnson et al., 2006). Authors also discussed a variety of possible reasons for assistive technology abandonment: families left out of evaluation and implementation, lack of communication, or families using other modes for child's communication.

### *Problem-solving with Speech Generating Devices*

With reliance on technology, problems will arise that need to be resolved. Parents reported a variety of issues when it came to ongoing device use. The largest problem reported was device breakdown occurring within the first year of



use (Shepherd et al., 2009). Approximately 40% of devices broke down and had to be sent in for repair and 66% broke down a second time within a five year period (Shepherd et al., 2009). Some of the problems reported about device use included: breakdowns, unpredictability, physical access, programming issues, upgrading the device, and speed of device. Device breakdowns and unpredictability made progress harder to achieve (Rackensperger et al., 2005). Settings can either encourage or discourage device use (Scherer & Glueckauf, 2005) and device users reported difficulty accessing the device in a range of settings (Rackensperger et al., 2005). Parents described the amount of time needed for programming was exacerbated by their lack of training (Bailey et al., 2006). Devices also were problematic in some social situations because of speed (Hodge, 2007).

Device breakdowns led some families to abandon the device for brief periods of time (McNaughton et al., 2008). Because of the nature of high technology SGDs, when they breakdown, they have to be shipped for repair. A study in Ontario listed the average repair turnover time at approximately ten months (Shepherd et al., 2009). As a result of long periods without a device, another outcome of breakdowns was slower progress due to lost time and recovery. Unpredictability of devices led to decreased participation. One adult device user commented that she didn't feel safe going into the community because her device was unpredictable and may not work when she needed it (Rackensperger et al., 2005). A few parents put off programming due to time and difficulty programming and have feelings of uncertainty about programming the device (Bailey et al., 2006). Helpful changes for SGDs included better technology

support (McNaughton et al., 2008), decreasing the weight of the device (Newton et al., 2006), and including families and individuals in the decision-making process (Rackensperger et al., 2005).

#### Familial Factors Influencing Speech Generating Device Use

SGD use varies family to family and even within a family. Because of the high percentage of devices abandoned each year (Shepherd et al., 2009), it is important to understand what factors may play a role in the decision of a family continuing to pursue use of SGDs. Familial factors that may determine SGD use within the home are: expected benefits (Bailey et al., 2006), device breakdown and unpredictability (McNaughton et al., 2008), training and support (Johnson et al., 2006), family feelings and perceptions about SGDs (Wielandt, 2003), child's needs not met or device not appropriate (Parette & Angelo, 1996), and parental roles, choice, and involvement in SGD use (Wielandt, 2003).

Within a child's SGD evaluation, families begin making predictions as to how and to what extent SGDs will provide their child and family with benefits. Parents may have many expectations without considering expectations of the family and what role the family will play in device use (Bailey et al., 2006). However, proficient use of SGDs to communicate requires practice and education (McNaughton et al., 2008). Parents who do not understand the amount of work that it takes to bring a child to proficiency will be disappointed (Bailey et al., 2006).

One of the important familial factors of SGD use is parental roles and involvement. There is a high level of demands on parents whose child uses an SGD (Goldbart & Marshall, 2004). Because of the lack of support and training,

parents end up having to find their own way, collaborate with others, be pushy with schools, or other desperate attempts to assist their child (Marshall & Goldbart, 2008). Parents take on programming SGDs, teaching their child how to use SGDs, along with other daily roles. The increased levels of stress, anxiety, and depression for parents of children affected by autism may not allow these parents to take on even more demands. Parents may become reliant on their close relationship to their child and deep understanding of the child and stop using SGDs.

Another factor that plays a role in SGD use is predictability and reliability of SGDs. Technology breakdowns and unpredictability were among reasons families briefly abandoned technology (Rackensperger et al., 2005). Some families stated a fear of hurting or breaking the device. A way some families worked through this intimidation of SGDs was through exploration and play on the device (McNaughton et al., 2008).

Training and support was another factor that may determine SGD use. Families showed concerns that they could not receive assistance when needed and how this increased stress related to programming and training (Bailey et al., 2006). Many families had trouble finding professionals who could support their child's SGD use (McNaughton et al., 2008). Support and collaboration with the family can decrease technology abandonment (Parette, Huer, & Brotherson, 2001). Families that received support and had an input into their child's device use were more likely to continue use (Johnson et al., 2006). Within laptop use for children with disabilities, training was listed as a top priority (Priest & May, 2001).

Finally, another important factor surrounding SGD use is how the child and family feel about use of SGDs. Many families stated their child liked their SGD (McNaughton et al., 2008). Children also showed technology use increased their motivation and enjoyment (Lindstrand & Brodin, 2004). As a result of liking the SGD or being motivated by it, the children would be more likely to want to engage in using SGDs. Families who already used and felt comfortable with mainstream technologies were likely to easily incorporate device use into family life (McNaughton et al., 2008). Interests and family experiences with technology also played roles in feelings about SGDs (Lindstrand & Brodin, 2004).

### Conclusion

Families using SGDs with a child who has autism go through a variety of experiences with SGD use and autism within the home environment (Brotherson et al., 1996). Improvement with SGD use for kids affected by autism is a huge motivator for families to use SGDs (Mirenda & Iacono, 2009). The ability to communicate and beginning to see aspects of a child's personality (Goldbart & Marshall, 2004); along with literacy (Koppenhaver et al., 2001) and behavior improvements (Glennan & DeCoste, 1997) are motivation for families to SGDs. However, parents also experience the use of SGDs as a stressor within family life due to lack of support and training (Bailey et al., 2006). Parents of children using SGDs become an expert not only about their child, but also about SGD use (Marshall & Goldbart, 2008). For families who have a child with autism, this additional role as programmer and teacher along with the other stresses, anxieties, and depression (Smith et al., 2010) that occur with parents raising a child with autism may be too much for families to handle. It is important to

understand experiences families have with using SGDs with a child who has autism to better understand daily SGD use (Granlund et al., 2008).

## CHAPTER III

### METHODOLOGY

Phenomenology is the philosophy that studies lived experience and phenomenologists are interested in studying how people experience certain phenomena (Bernard & Ryan, 2010). Smith, Flowers, and Larkin (2009) explained how “true” meanings of lived experiences are not fully attainable due to the fact that “the experience is itself tantalizing and elusive” (p. 33). However, phenomenologists seek to understand phenomena by coming as close to the experience as possible. This is achievable through the exploration of experiences from the study participants (Smith et al., 2009). Specifically, Interpretive Phenomenological Analysis (IPA) allows researchers to engage in a recently developed approach to phenomenological work that allows for an interpretive, or hermeneutic, element while maintaining a rigorous, recursive focus on the lived experiences surrounding the phenomena of study.

Interpretive Phenomenological Analysis (IPA) is an analysis that has three core origins: phenomenology, hermeneutics, and idiography (Smith et al., 2009). Each of these three philosophies is important in the origination of IPA. Phenomenology, and specifically the aim of describing the “essence” of lived experience, originated with the German philosopher Husserl, is an important aspect of IPA because it foregrounds the bracketing (Bernard & Ryan, 2010) of researcher subjectivities in order to observe and describe lived experiences related to a specific phenomenon (Bernard & Ryan, 2010). In other words, Husserl believed in order to study the lived experiences of subjects, one must set aside her own experiences and focus objectively on participants’ experiences.

Husserl (1999) explained this reflection on experiences, “Focusing on experiencing gaze on our own psychic life necessarily takes place as reflection, as a turning about of a glance which had previously been directed elsewhere.” (p. 323) Husserl also believed that part of understanding the meaning of a phenomenon includes a recursive process of thinking through experiences again and again, with a specific emphasis on the process of thematic reduction.

This is where specific steps of IPA become productive as a methodological approach, processes such as the recursively categorizing data, reducing categories into themes, and purposefully searching for divergent themes (Smith et al., 2009). Though it continues to focus on the meaning of lived experience, IPA differs from phenomenology by allowing for interpretive work, knowing any meaning applied to the study of lived experiences is at least in part interpretive. According to IPA, the true essence of a lived experience is not attainable, but meaningful steps can be taken towards the lived experience essence through bracketing, asking phenomenological questions, six specific steps of iterative analysis and thematic coding, and focusing on descriptive representation rather than explanation.

The second major tenet underpinning IPA is hermeneutics, which involves rigorous interpretation of text. Through hermeneutics, IPA is brought back to the actual text and the interpretation of the text. Moustakas (1994) states how the interpretation is important because “Interpretation unmask what is hidden behind the objective phenomena.”(p. 10). By reading parts of the whole, the researcher engages in hermeneutic circles that enable one to understand the essence of the experience (Moustakas, 1994). The focus of hermeneutic circles is

the use of a recursive process which wrestles with multiple meanings existing within a given text (Smith et al., 2009). Hermeneutic circles allow the researcher to take an empathetic stance and see the world through the participant's eyes while also being able to step away from the participant's experiences and analyze the participant's experiences (Smith et al., 2009).

The third and final underpinning of IPA is idiography. Idiography is the study of the specific (Smith et al., 2009). So instead of being interested in what a large group of people experience, as common in ethnographic studies of shared cultural experiences, IPA is interested in the very specific experiences of a few surrounding a single common phenomenon. This permits IPA to take an in-depth look at a small group who share a common lived experience, in this case families with children with autism who use speech generating devices, instead of a broad look at a large group of people. It is important to keep the number of participants small in order to be able to analyze the data thoroughly (i.e. six to eight participants) (Smith et al., 2009). Because of the in-depth look at a small group of people, idiography also implies a stringent analysis of the in-depth experiences of this small group. With a focus on depth, IPA provides a systematic procedure involving six steps of data analysis.

Husserl developed bracketing as a way to set aside one's own thoughts and feelings in order to focus on the specific experiences of a phenomenon (Bernard & Ryan, 2010). Maxwell's (2005) description of using memos during qualitative research is an example of a way to bracket one's feelings and perceptions in order to engage and conduct data collection more objectively. Bracketing is important because it permits the researcher to step away from his



or her own bias. The process of bracketing was described by Heidegger as a cyclical process (Smith et al., 2009).

IPA is a productive way to analyze participants' experiences because it allows the researcher to engage without bias through bracketing, see the participants' experiences within the text, and gives flexibility for the researcher to engage in a recursive process that leads to an understanding of the phenomenon (Smith et al., 2009). Though bracketing one's subjectivity doesn't fully eliminate bias, additional analytic processes (i.e. the use of additional coders) during coding help validate the trustworthiness of the researcher's findings. IPA allows the researcher to understand the experiences of a phenomenon while being able to engage in bracketing to an extent. The use of interpretive phenomenological analysis allows the researcher to engage in a rigorous process of a "double hermeneutic" (Smith & Osbourne, 2003). Smith et al. (2009) describe this process "The researcher is making sense of the participant, who is making sense of x." (p. 35). This process of IPA is completed using a six-step method that makes the analysis from within the texts of the transcripts rather than an analysis from outside the texts.

A phenomenologically-oriented study that uses IPA to analyze data allows bracketing personal thoughts and feelings about SGD use within the home for children with autism, but also allows an opportunity to understand experiences families have through analyzing open-ended interview question responses. Open-ended questions allow the participant to determine how to answer a question without the researcher leading him or her in any specific direction. So, an example of an open-ended question would be, "Tell me about your

experiences with Clay and his sister,” whereas a closed-ended question of the same scenario might be, “It must be hard to get Clay to interact with his sister. Can you tell me about that?” The second question implies that there is something that makes Clay’s interaction with his sister difficult, whereas the first one allows the parent to talk about any experience he or she thinks of.

This study came about after I completed a pilot study that centered on experiences parents have with a child who has autism and uses a speech generating device to communicate. In my pilot study, I interviewed eleven parents over the phone one time for a period of approximately one hour. Parents discussed how their child used a device within the home, community, school, and therapy environments. Parents also discussed the AAC evaluation process for determining whether a speech generating device would be beneficial for their child, determining which device would meet their child’s needs, and aspects of device technology within the home, such as programming the device. My pilot study helped inform the current study because I found out about the child’s evaluation for a speech generating device, how devices are incorporated into school and private therapy, and a snapshot into family life with a child who has autism and uses a speech generating device. However, I wanted to find out about device use on a regular basis within the home; what it looks like, how it works for the family as a whole, and how it looks and functions in situations where families have been using a speech generating device for a period of longer than a year. Families using SGDs longer than a year were important because of the research that states 30% of technology abandonment occurs within one year of receiving technology (Johnson et al., 2006).

Specific examples of the IPA coding process, namely the stages it entails, and how these steps claim rigor and validity, are examples from the current study.

### Problem and Purpose Overview

The Participation Model (Beukelman & Mirenda, 1998) states that all individuals want to communicate and assistive technology can be used to facilitate individuals with disabilities' communications. When the Participation Model began being used in the 1990's, it allowed individuals with severe disabilities, including autism, to be considered for assessment and use of assistive technology through individualized education plans in schools without having to meet any prerequisites (Hourcade et al., 2004). As a result of the Participation Model, augmentative and alternative communication, including speech generating devices, began to receive recognition as communication interventions appropriate to use with individuals who have autism (Schlosser & Blischak, 2001). Individuals with autism began utilizing speech generating devices to assist with communication needs at school and improved communication skills (Olive et al., 2007; Son et al., 2006).

Children with autism can use speech generating devices to assist them in communicating (Olive et al., 2007; Son et al., 2006). However, there are little to no studies that explore in-depth the complexities at play nor sustainable longevity of SGD use in families raising a child with autism. Technology abandonment remains an issue within the use of assistive technology for a variety of reasons, such as family members not involved in decisions (Brotherson, Cook, & Parette, 1996), lack of support or training (Johnson et al., 2006), and not meeting the

needs of the person, too much time or effort, and the device being socially unconventional (Scherer & Glueckauf, 2005). Because assistive technology abandonment rates occurs in approximately 30% (Johnson et al., 2006) of families within the first year, it is important to understand family experiences with SGDs and what factors may play a role in the sustainability of SGD use.

Through the use of IPA, the researcher gains an understanding of the lived experiences of families raising a child with autism who use SGDs over a sustainable amount of time and better understands how these experiences fit into the longevity of SGD use.

#### Research Question

The following phenomenological research question examines the lived experiences of families who have children with autism who use SGDs: *What are the lived experiences of families with children with autism who use SGDs?* The specific data collection and analysis procedures that stem from this phenomenological question explore factors surrounding the ongoing use of SGDs in families' daily lives. One parent from each family was interviewed and asked to speak on behalf of the family as a whole.

#### Research Statement

The purpose of the current phenomenologically-oriented qualitative study is to describe the lived experiences of a group of families regarding the ongoing use of SGDs within the home for children affected by autism. IPA allows the researcher to understand family experiences regarding children with autism using SGDs and make sense of the family experiences. Smith et al. (2009) describe this process as , “wanting to stand alongside the participant, to take a look at

them from a different angle, ask questions and puzzle over things they are saying”(p. 36). This description explains how IPA combines phenomenological and hermeneutic approaches (Smith et al., 2009). Interpretive Phenomenological Analysis is best suited as a research approach for this current study because it enables the researcher to look at the complexities surrounding autism and the use of SGDs which leads to identifiable themes that allow rich descriptions of the data.

### Population and Sample

Participants were selected from the Center for Augmentative and Alternative Communication (AAC) & Autism’s database. Criterion included children who live at home with parents or caretakers, have a diagnosis of Autism Spectrum Disorder, have been using a speech generating device for a minimum of one year in the home, and the child with autism is between the ages of two and twenty-one. The broad age range is needed because the group that is being studied (children who have autism and use speech generating devices) is a small group among children who have autism. Participants live in different areas of the United States. Informed consent was obtained through the informed consent letter. Pseudonyms were used to protect the privacy of the participants.

Selection strove to include a variety of racial and ethnic groups. Selection criteria used *purposive sampling* (Patten, 2005) to receive participants that meet the above criteria and included approximately 6-8 participants. According to Smith et al., (2009) a typical number of participants to complete an in-depth Interpretive Phenomenological Analysis (IPA) is approximately six to eight. Including additional participants ensured adequate participation in case of losing

participants during the process of the study. Because of the nature of an Interpretive Phenomenological Analysis, the ideal number of participants should be kept small to allow for the rigorous data collection and analysis, which includes a six step process of in-depth interviewing, line-by-line coding and a paramount focus on recursivity and validity checks through IPA procedural analysis (Smith et al., 2009).

#### Data Collection and Instrumentation

All interviews took place via phone or University of Southern Mississippi's (USM) Blackboard Online Classroom forum and were recorded. In order to ensure comfort, participants can call or connect online, may type answers, use a microphone, or use the phone to respond. Participants were reminded that information shared was confidential and the researcher would not distribute identifying data. A recorded archive of all interviews was saved for transcription verbatim.

Each participant participated in two weekly interviews, with a specific day and time scheduled. During weekly interviews, participants engaged in a semi-structured interview regarding family experiences living with a child affected by autism who uses a speech generating device to communicate. All interviews were conducted in a phenomenologically-oriented manner, with the openness for the researcher to ask for more information regarding information that comes up during the interview (i.e. Tell me more about that. How does that go?). Interview questions are available in Appendix A. This phenomenologically-oriented interviewing method allows the participant to lead the conversation and the

researcher would ask additional probing questions about the information given with the language used by the participant. An example of this is given below.

M: Sometimes Jefferson gets stuck in a motor plan. Like "more tickle" (laughs) that's all he wants. (R laughs) and if it's not appropriate for tickling, then I'll hide tickle. You know, he doesn't get to choose that. That sounds kinda mean, but he has, you know if we need him to be doing something else then I'll hide tickle. But he's smart and he realizes tickle under his ABA page and he'll go find it there.

R: (laughs) And so what happens in that kind of situation?

M: well, then he gets tickled. (R laughs) we get he gets tickled b/c then you're like, "oh my geez the kid worked so hard, you know?" We do tickle him and but then just try and say, I might model like "oop, have to to stop or all done with tickles time to eat." Like that happened at the when we were out to breakfast and he was getting tickled before the food arrived. And then, once it arrived, he was like "ok, more tickle" and we were like "no, it's time to eat" you know, "stop, all done on tickle" now you have to eat. You know, or drink juice or eat pancake so

### Data Analysis

Interpretive Phenomenological Analysis (IPA) is described as a six step process of analyzing data. As phenomenological research is defined, it describes a recursive process, where the researcher looks at the phenomenon, notices and codes for categorical similarities, and looks again, repeating this process for an understanding of the lived experiences of a group of people (Moustakas, 1994). In other words, the process of using IPA allows the researcher to study the

described phenomenon through a highly recursive analytic process that brings a closer understanding of the lived experiences of the group of people being studied (Smith et al., 2009). Table 1 outlines the six step process of analyzing data according to Smith et al. (2009). A detailed description of each step follows the table. Specific examples of the IPA coding process, namely the stages it entails, and how these steps claim rigor and validity, are examples from the current study.



Table 1

*Six Steps of Interpretive Phenomenological Analysis (IPA)*

Step Number	Step Description
One	Reading and re-reading
Two	Initial Coding
Three	Developing emergent themes
Four	Searching for connections across emergent themes
Five	Moving to the next case
Six	Looking for patterns across cases

The first step is reading and rereading of the transcripts to gain a deeper understanding of how the participant understands a phenomenon (Smith et al., 2009). Through this first cycle coding, the researcher listened to and or read the transcripts multiple times before beginning to code the data. This step also included the transcription of the interview, the data cleaning of the transcript, and sharing each interview transcript with the methodologist. Participants received a copy of each transcript to read the transcript and add any pertinent information or clarify something said. As part of the process, the researcher bracketed personal feelings about the research subject and project to allow less biased analysis and understanding of the participants' views and understandings, specifically acknowledging and removing researcher preconceptions. During the bracketing

stage, the researcher wrote or recorded memos, allowing the researcher to help further set aside biases and personal feelings towards the area being researched (Maxwell, 2005).

By utilizing memos as a part of the pilot study, it allowed me to write out my personal thoughts and feelings as I began working on interviewing, transcribing, reading, and rereading the interviews. As a part of this process of memoing in an attempt to remove my bias through bracketing myself out of the picture, my aim was to deposit my feelings in a safe place, which allowed me to focus on the interviews and how the experiences the parents are having informs the IPA. Throughout the entire process of the phenomenologically-oriented study, it remains important to continue to bracket myself away from my own experiences so that I can stay focused on the participants and the themes that emerge from within the interviews and transcripts, instead of emerging from my own biases and experiences. In addition, I continued to bracket for personal experiences through close readings and rereading, coding and recoding to determine categories and themes emerging from interview transcripts, and purposefully looking for divergent themes throughout the data in efforts to “check” my thematic work.

After reading and rereading, the second step for data analysis using IPA is first cycle coding. This process is a very close reading of the transcript in order to look at what is being said line-by-line (Smith et al., 2009). The researcher takes notes on what is said, but stays very close to the original meaning by the participant. The participant’s words lead the way through this first cycle coding. Smith et al. (2009) state three types of comments may be used during this step:

descriptive, linguistic, and conceptual comments. Descriptive comments simply describe what is being talked about. The second type of comment that may be a part of the first cycle coding is linguistic comments. These are comments that are made about the speech, tone, word choice, along with silence, hesitation, and laughter used by the participant. Linguistics comments may be written down for whatever reasons it catches the researcher's attention. The third type of comment made during initial coding is a conceptual comment. A conceptual comment may lean more towards the broader picture of the research or personal questions or thoughts the researcher may have at this point.

As part of the second stage, I closely read and reread the transcripts and made notes in the margins. After completing initial coding, I reread the transcript again on a line by line basis and highlighted phrases, sentences, and paragraphs as a precursor to the third step. Once I began the third step, I went back to highlighted sections and reread line by line again for emergent themes. By completing the second and third steps in this fashion, I found that it allowed me to better focus on the interview and the participant's thoughts rather than getting caught up in the development of emergent themes. I felt that my emergent themes were allowed more room to emerge on their own by completing the steps this way.

Thirdly, the researcher begins to develop themes according to what topics continue to resurface within one interview and later, throughout multiple interviews. At the same time, the researcher is also remaining open to divergent topics, or how the participant's views may differ throughout one interview or how participants' views differ. It is important to focus on divergence as well as

convergence in order to validate your data (Smith et al., 2009). Seeking divergence is important as an analytic tool and helps break down words, phrases, and sentences used by the participant, enabling opportunities to look at how a transcript by itself has similarities and differences in addition to how multiple transcripts are similar and different. Utilizing divergence is another way to make sure the researcher remains focused on the experiences of the participants and is not unconsciously looking for what he or she wants to find. The researcher begins to use the initial coding comments as parts to interpret the whole interview. This process begins to include the researcher as interpreting the data, as if the researcher and participant are combining efforts to understand the experiences of the participants. The researcher interpreted (using IPA's very specific set of analytic steps) what the participants were sharing about their lived experiences (Smith et al., 2009). The following is an example of how this process may look.

Table 2

*Initial Coding*

Line Number	Emergent Theme	Quote
269-271	Device use	he's able to get his point across. Especially if it's a tangible item. Like you'll see on his Aug comm, he'll ask for a cd. And what that means is he wants a DVD. Because the icon for the CD looks like a DVD
272-273	Nonverbal communication	I'll say, "Ok which one?" and he'll go in and he'll get the one he wants & then, he hands it to me
279-280	Food/drinks/movies	mainly, to specifically ask for a snack, popcorn, pretzels, drinks, iced tea, milk, juice...to watch a movie, like I said about the DVD and the CD.
280-285	Breakthrough, accomplishment, Mom's excitement	I'm trying to think, what did he...OH! He actually, for the first time, when he picked out his DVD, he typed in "I like that" and I was (R: cool) like WOW! That's pretty impressive

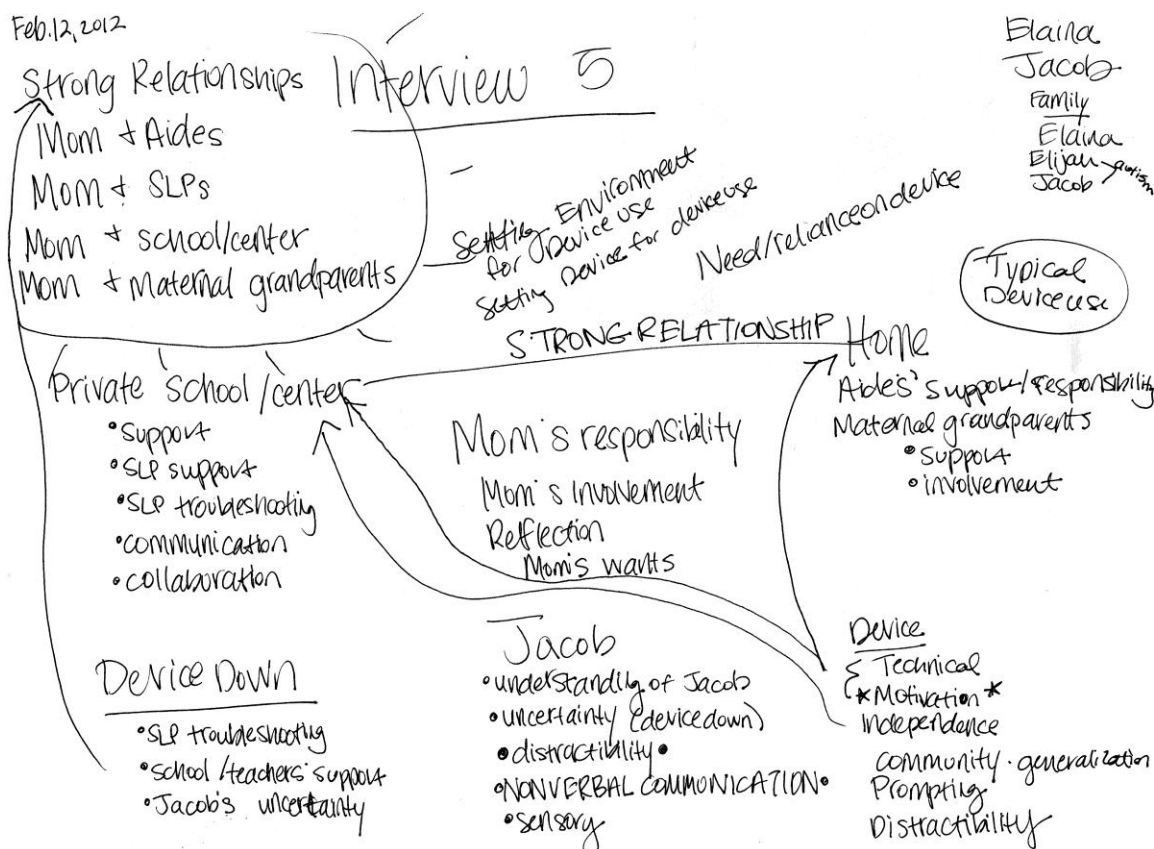
Table 2 (continued).

		(laughs) YOU LIKE THAT! (R laughs) AWESOME! I knew you liked this movie (both laughing) 'cause you ask for it all the time! So, that was HUGE for me. I was like, I like that! YAY! GOOD JOB!
285-286	Improvement, Food/snacks/DVD	So primarily, it's for food items, snack items, and to let me know that he wants a DVD. But we're, we're we are improving tremendously!
289-292	Getting family on board, Device use at school, Device availability	I think the hardest thing has always been. When he was going to school, and his device would go to school with him and then come home in the afternoon, was getting my family to understand how important it was to make his device available to him 100% of the time

The initial coding is a close line-by-line reading of the transcript (Smith et al., 2009) where the researcher begins to analyze the data. During the initial

coding, the researcher is beginning to familiarize with the transcript and interpret meaning. This step is time-consuming but important—it is paramount to read transcripts closely, engaging intimately with the text (Smith et al., 2009). For me, it was important to engage in close readings of the text and consider all of the possibilities of what the participant was telling me or what the information the participant gave me was saying.

The fourth step is an organization of themes. This step brings the researcher back through a recursive process of looking at individual interviews again. It reduces reoccurring information into themes. This step organizes the emerging themes in order to construct meaning and understanding from the transcript or transcripts. The fourth step for me involved a large dry erase board and the organizing of how the emergent themes work together or do not work together. After using the dry erase board, I copied the emergent theme organization onto paper. Figure 2 is a sample of what this organization looked like.



**Figure 2.** Organization of Interview Five. This figure shows an example of what the organization of an interview in step four of IPA looked like.

Step four allowed exploration of the emergent themes and making connections of how emergent themes were similar, different, connected, disconnected, and neutral. Being able to visually organize the interview and emergent themes brought to light a different form of understanding through changing the way I viewed the emergent themes. This step also included meeting with my methodologist and talking through the emerging themes. By sharing and talking through each interview, it helps increase intercoder reliability in that the emerging themes were not just what I may want to see or choose to see. Talking through the interviews allowed me to include quotes from the participant and reword the interviews in order to connect the emerging themes back to the text. The fifth step involves beginning steps one through five again with the next transcript.



Smith et al. (2009) warn researchers to remain open-minded and treat each case separately. The sixth and final step involves looking at all of the transcripts together and looking for themes across the interviews, making sure to include convergent and divergent information, as this makes a richer, more realistic view of the interviews together. The use of more than one coder increases confidence in emerging themes through intercoder reliability (Bernard & Ryan, 2010). By allowing other research advisors (i.e. qualitative methodologist) to code alongside me would further validate emergent themes and bracketing within the current study. This would also allow comparisons within codes, themes, analyses for similarities and differences.

### Summary

Within a phenomenologically-oriented methodology, Interpretive Phenomenological Analysis permits the current study to take an in-depth look at a small group of families and explore the experiences they have had raising a child with autism who uses a speech generating device to communicate. Through idiography (Moustakas, 1994), the researcher had an understanding of rich experiences the participants have had. The rigorous six-step process of IPA ensured that the researcher brackets personal thoughts and views in order to understand the experiences families have utilizing speech generating devices with a child affected by autism. Interview questions were open-ended and allowed the participant to lead the discussion and select directionality (Smith et al., 2009) The IPA recursive process was used to analyze the data through the use of Hermeneutic circles and close reading of the text.

## CHAPTER IV

### ANALYSIS OF DATA

The purpose of this qualitative phenomenological study was to examine the experiences of families with a child with autism who uses a speech generating device to communicate. Previous research has explored mothers' perspectives on their family's experiences raising a child with autism, and growing up with a sibling who has autism, but there is no research reported specifically about children who have autism and communicate through the use of speech generating devices.

This chapter begins with an overview of the organization of the data analysis and research question. Next, a brief description of each participating family is provided. Finally, the five super-ordinate themes that emerged are described within the use of Interpretive Phenomenological Analysis (IPA).

#### Organization of Data Analysis

An introduction to the families is provided first in order to become familiar with each family, the parent who was interviewed, and the child who will be discussed. Next, the five super-ordinate themes which emerged from the phenomenological research question are introduced and explored. The super-ordinate themes that emerged through the use of IPA are discussed in no specific order, as not to emphasize one super-ordinate theme as more important than another. The first super-ordinate theme represents the overall complexities within using a speech generating device with a child who has autism within multiple settings and people. The second super-ordinate theme describes the tensions between the structure that is needed for children with autism and the

parent's desire for spontaneous play with their child, while the third super-ordinate theme illustrates the relationship between requesting language and social communication. The fourth super-ordinate theme presents the various roles of advocacy the parents play while the fifth super-ordinate theme highlights the importance of building a support group.

### Research Question

The following research question guided this study: *What are the lived experiences of families with children with autism who use SGDs?*

### Introduction to the Families

Six parents across the United States participated in two semi-structured phone interviews, sharing family experiences with their son or daughter who has autism and uses a speech generating device to communicate. The parent being interviewed was asked to speak on behalf of the family. All participants were middle-class, Caucasian parents raising a son or daughter with autism. However, London's family adopted Alice from another country. Five mothers and one father were interviewed. Four families have a son and two families have a daughter. Pseudonyms were used to protect the privacy of the families that participated.

Table 3

*Child Background Information*

Parent	Role	Age		
Child	Gender	Age	Diagnoses	Device Name
Caroline	Mother	37		
Tristan	Male	8	Autism, Partial seizure disorder	Springboard Lite
London	Mother	51		
Alice	Female	17	Autism, Intellectual Disabilities	Vantage Plus
Moira	Mother	37		
Jefferson	Male	4	Autism, Dysgenesis of the Corpus Callosum	Vantage Lite
Nadine	Mother	44		
McKinley	Male	14	Autism, Angelman-like syndrome	Springboard
Elaina	Mother	33		
Jacob	Male	3	Autism, Mitochondrial Disorder, Hypotonia	Vantage Lite
Zachary	Father	44		
Kennedy	Female	9	Autism	Vantage Lite, WordPower software

### *Caroline and Tristan*

Caroline is 37, Caucasian, and has a bachelor's degree. Caroline shared her family experiences with her son, Tristan. Tristan is an eight-year-old boy who lives at home with his mom and dad. Tristan has a diagnosis of autism and partial seizure disorder. He attends a public school in the Midwest U.S. and is in a special education classroom for children with autism. Tristan also receives in-home Applied Behavior Analysis (ABA) therapy after school.

Tristan's dad is a stay-at-home dad, while his mom travels a lot for her job. Tristan communicates his needs and wants using his Springboard Lite which he has been using for approximately a year and a half. Tristan primarily uses his device to request items such as snacks, drinks, and food. He also uses it to request his iPod, mom and dad, and TV shows like *Fresh Beat Band* and *Yo Gabba Gabba*.

### *London and Alice*

London is 51, Caucasian, and has a bachelor's degree. Her daughter, Alice, is a 17-year-old young lady who lives at home with her mom, dad, and brother. She was adopted from another country when she was 26 months old. She has a sister that is grown and has moved away. Alice is diagnosed with autism and intellectual disabilities. Alice is a senior in a public school in the western U.S. in a special education classroom. Alice has been using a SGD for approximately 12 years and is currently using the Vantage Plus.

Alice uses her Vantage Plus to fulfill her wants, needs, request personal items, and socially communicate in a variety of settings using scripts. Alice likes to play with a Koosh ball and enjoys interacting with people after church is over.

Alice is at a different life-stage than the other children in this study; she is about to complete high school and begin some sort of job.

*Moira and Jefferson*

Moira is 37, Caucasian, and has a bachelor's degree. Her son, Jefferson, is a four year boy who lives at home with his mom, dad, brother, and twin in the Midwestern U.S. Jefferson is diagnosed with autism and dysgenesis of the corpus callosum. He is in an early childhood class part of the day and receives ABA therapy in his home in the afternoons. Jefferson has been using a SGD for a total of approximately a year and a half and has owned his Vantage Lite device for one year.

Jefferson uses his Vantage Lite to communicate wants, needs, and is beginning to use it in a variety of other ways such as to socially communicate and comment. Jefferson's mother describes him as an active child who very much enjoys highly sensory-oriented activities like climbing and swinging.

*Nadine and McKinley*

Nadine is 44, Caucasian, and is currently in college. Her son, McKinley, is a 14-year old young man who lives at home with his mom, dad, brother, and sister. He has a sister that is grown and has moved away. McKinley has a diagnosis of autism and Angelman-like syndrome. McKinley is currently in a home and hospital program in the northeast U.S. where he receives special education services in his home two days a week and at school one day a week. In addition, he receives speech therapy biweekly and occupational therapy once monthly at his neighborhood school while he is getting ready to transition into a new school.

McKinley uses a Springboard to communicate wants and needs. He has been using his Springboard for four and a half years. Nadine describes a special relationship with McKinley. She describes that he uses his Springboard to show his sense of humor. For example, Nadine says, “he would always push his buttons to say ‘go outside to the bathroom’ and just giggle.” McKinley loves watching the sun filter through the trees and pays attention to the little details.

#### *Elaina and Jacob*

Elaina is 33, Caucasian, and has a bachelor’s degree. Elaina’s son, Jacob, is a three-year-old boy who lives at home with his mom and older brother. Jacob has a diagnosis of autism, mitochondrial disorder, and hypotonia. Elaina is a single mom raising two boys with autism. However, Elaina has three aides that rotate and assist her with the boys four nights a week.

Jacob attends an early intervention classroom at a private school for children with autism in the Midwestern U.S. Jacob has been using a Vantage Lite for two and a half years. Jacob, like Jefferson, is a very sensory seeking child, and enjoys swinging, bouncing, crash pads, along with toys such as *Sesame Street* and *Nick Jr.* characters.

#### *Zachary and Kennedy*

Zachary is a 44 year old Caucasian man with a master’s degree. His daughter, Kennedy, is a nine-year-old girl who lives at home with her mom, dad, and brother. Kennedy is diagnosed with autism, and her brother is diagnosed with Asperger’s Syndrome. Zachary talks about the “division of labor” within their home; he and Kennedy go one way and his wife and son go the other. Kennedy is in a publicly funded private ABA school in the northeast U.S. Kennedy is using

a Vantage Lite with WordPower software. She has been using her Vantage Lite for two and a half years. Zachary describes Kennedy as enjoying car rides and outings to the mall and playgrounds. Kennedy uses her device throughout the day for a variety of reasons: choosing what to eat and drink, what toys to play with, which movies to watch, and when to take a bath and go to sleep.

Six participants who are parents of a child with autism who use a speech generating device to communicate participated in the current study. All of the children used a high technology speech generating device and had been using the device for a period of one or more years. Ages of the child ranged from three to seventeen and included four boys and two girls. All families were from a middle-class, Caucasian background. All participants were the biological parents of their children with the exception of London, who adopted Alice from another country. Five of the six families were married couples with one single parent represented. Five of the six participants had other siblings living within the home and two of the families had another child with an autism spectrum disorder.

### Analysis of Data

Through the use of Interpretive Phenomenological Analysis (IPA), five super-ordinate themes emerged within the analysis of the interviews. The super-ordinate themes that emerged are: the complexity of SGDs as tools for communication, tension between structure and play, the interplay between requesting and social interaction, the fluctuating role of the parent advocate, and building a diverse support network. Each of these sub-ordinate themes is discussed in the follow sections. It is important to note that the themes are not hierarchical, however are presented in a natural progression of themes.



### *The Complexity of SGDs as Tools for Communication*

The first super-ordinate theme that emerged is the complexity of SGDs as tools for communication. This includes the overarching need to depend upon an inanimate object (the device) by the person who relies on it to communicate. Just as a typical child's language is constantly changing as they develop, the interplay of device use and language development appears to be a multifaceted part of the ever-changing development for the group of children studied. This is further complicated by the underlying goals for using the device, not only by the user but also by his or her parents and professionals. Parents shared a spectrum of goals for their child through device use which correlated with their child's age and development. In addition to learning to *use* the device, the child and family must also learn to *manage* the device (including programming and repairs). The reliance on technology also adds another aspect of how devices are complex because technology does malfunction, break, and have periods of instability. As the device is used over time (the group of children studied all have used SGDs for more than a year), there are fluctuating periods of device use, with periods of regression and growth.

#### *Differences in speech generating devices use between parents.*

One of the aspects of the complexity of SGDs as tools for communication is the difference between SGD uses of parents. Four parents described unequal responsibilities within device use, while one parent described a shared responsibility. Elaina did not elaborate on differences in responsibilities with SGD use because she was a single mom. Five of the parents discussed aspects of

how they experienced device use with their child and how they experienced device use between their spouse and their child.

Within the family structure, differences between how the mom and dad utilized the device with the child surfaced as part of the complexity of device use. Because Elaina was a single mom, the responsibilities of device use between parents weren't explored. She stated: "so every other Sunday, he's with his dad. I don't exactly know what they do, but he does take the device with him. So, I'm assuming that he uses it during that time." Four of the parents felt like the majority of device use responsibilities fell on the mother, while Zachary described a mutual responsibility between his wife and himself in this way.

Affects the frequency of it really. I mean I spend more time with her. So I have a lot more opportunities to reinforce and generalize her using, using the device. My, my wife is with my son more and is around Kennedy less and so she has fewer opportunities...but I don't think it... changes the nature of it in any way. (Personal Interview, January 20, 2012)

While Zachary felt that he and his wife shared the responsibilities of device use, the other four married parents did not feel that the responsibilities were shared.

Not only are responsibilities perceived by four of the parents as unequal, but communications are described differently also. Because of Nadine's special bond with her son, she described her interactions with McKinley differently than her husband's: "usually my husband will have to say 'Go use your voice. Go get your voice.' And then, he will go. But I'm trying to think if he brings it to him, like he brings it to me. I can ask him because he's home." Nadine asks her husband

and then reported “Yeah, he says he doesn't bring it to him. He usually has to tell him to go get his voice.”

Another example of parent communications with the child differing based on which parent was interacting was London's explanation of her husband's device use.

He was slow to use the device with her at first when she was younger, but now because (laughs) she's used it ALL these years, he, he knows to prompt her “I don't know what you want.” He will, he will respond to her gestures or her pointing and not make her use the device if he thinks he knows what she wants. Which we're trying to condition him to (laughs) to make her use her words because she's not always gonna have people around that know these gestures and points that she does. (Personal Interview, December 28, 2011)

London described her husband's use of the device with Alice had changed over the years, but he still relied on gestures and nonverbal communication at times. Caroline and Michael's device use with Tristan also showed the complexity of SGDs as tools for communication in the sense that their approaches look and function differently. Caroline had structured times for Tristan to use his device, while Michael's times using the device appeared to be more play-oriented. Caroline described a text she received about an interaction Michael had with Tristan:

And I'm pulling up the text because I wanted to remember this. So this is Michael's text: “We've been watching *Sponge Bob*. He went and got his words and started hitting “play.” So we play. Then I go in and get his box

of toys and change the show to *Fresh Beat*. He chuckles, picks up his words, & while the theme song is playing says "watch video *Fresh Beat Band*," looks at me, and laughs." So they had a great interaction there where they were, he requested play with dad .Then he, Michael changed the show to *Fresh Beat Band* and he grabbed his words and said *Fresh Beat Band* and then made that eye contact which is a really good interaction. (Personal Interview, December 20, 2011)

This interaction Caroline described occurred within a time when Tristan had down time. Tristan and Michael's play appeared natural and laid back. In contrast, here is an example of a typical interaction between Tristan and Caroline.

We go downstairs; the first thing he wants is breakfast so I get out the device. I set the device specifically for breakfast food items that I know he's going to want to request. So I'll put waffles, eggs, toast, bacon, on the device and I might have a couple of other odd items like potato chips and pretzels or something like that. And he, I set it out and I will ask him "what do you want for breakfast?" and he grabs the device and says "eat bacon" (Participant Interview, December 12, 2011)

While Michaels' interaction with Tristan appeared to occur naturally, Caroline's interaction was purposeful and structured within the routine. These are examples of the complexity of device use within the home among parents.

Among the families in this study, four parents experienced differences between how they perceived the responsibility of the device between their spouse and themselves. However, Zachary described his experiences as shared

responsibilities with his wife. All five married parents described some sort of difference within SGD use with their son or daughter between spouses. The four married mothers described unequal device responsibilities between themselves and their husbands, while the father described times when his wife was more in sync to Kennedy's device use than he was.

*Parental goals.*

Parents in this study had set a variety of goals for their child's communication utilizing SGDs. Goals for device use may add to the complexity of SGDs as tools for communication because of parent expectations of the ultimate outcome that may or may not be attainable. Research stated parents with device expectations without the understanding of the work needed to provide the child with the opportunities to meet expectations, would be disappointed (Bailey et al., 2006). However, parents in this study appeared to have a clear understanding of their child's abilities and set attainable goals for their child.

London mentioned goals for Alice such as "help her use her talker functionally in the community" and "I want her to be able to use her talker if she comes across problems or concerns that she has so that she doesn't engage in negative behaviors in those settings." However, one of Caroline's goals for Tristan was more short-term:

I think the one challenge that we have is leaving all of the buttons open, having to manipulate the buttons a lot. Our goal is to not have to do that anymore - to just leave all of the buttons open all the time. (Personal Interview, December 12, 2011)

Leaving the buttons on the device open would allow Tristan more access to more vocabulary and it would also decrease the difficulty of daily use of the device.

Caroline described that her husband, Michael's device use may be reduced because he doesn't understand how to hide and show buttons. If Caroline were able to eliminate hiding and showing buttons, that would possibly allow Michael to use the device with Tristan more.

Parents' goals also included social interaction, social communication, and independence. As parents set goals, there was an unspoken comparison as to what their child does versus what was considered typical or normal. Caroline talked about a personal goal she had for Tristan:

My goal is for him to be able to independently carry the device from one person to another and make a request. Specifically that he wants. Where right now, he may be across the room or in the kitchen and I'm sitting on the couch in the living room and he's in the kitchen sayin' "eat waffles." I want him to know one of my goals for him is to be able to walk to a communication partner and use his words appropriately (Personal Interview, December 20, 2011)

Caroline's goal encompassed a variety of desires for him to appear more typical within his social interaction, communication, and independence. London shared a similar goal, "that's one of my biggest goals for Alice is to be able to communicate. That's her weakest skill." Alice did use her device to communicate her wants and needs so this statement acknowledged that London considers communication more than requesting wants and needs.

Elaina's previous experiences with device use and her older son may have altered her perceptions of device use when she began device use with Jacob. Elaina described a disappointment within Jacob's device use as compared to his brother.

You know, it's been up and down for him. He's not actually made as much progress as I maybe would have hoped he had. Because he had access to it at such a young age and Elijah didn't. Yet by the age, by Elijah's fourth birthday, he was making sentences on it. And Jacob will be four in two months and still using, usually only using one word, occasionally a two word combination. (Personal Interview, January 13, 2012).

A divergence from expectations of the child's device use was clearly portrayed through Moira. Moira described situations when the device would be modeled for Jefferson, but without any expectations on Jefferson's part.

Well, if he doesn't seem like, he's doesn't know what we're wanting then we model it and so forth. Model it into the talker. I guess I, I do a lot of modeling when we're out in public too because you become an interesting spectacle (laughs) when you have this. Especially our, we live in a rural area. And or even just being in the museum yesterday, or whatever and just to give give him an opportunity and others too like this "oh you know, what's going on?" So we do a lot of modeling there and I think it's just its modeling often most of the modeling is with no expectation for Jefferson.

(Personal Interview, December 29, 2011)

Moira took the opportunity when modeling for Jefferson to not only model with no expectations, but advocated the device within the community. By modeling

device use in the community, Moira was showing Jefferson and unfamiliar people that she can use the device as well and normalizing it within her family.

Parents set a variety of goals within device use for their child. Goals included more independence and social interaction. Parental goals diverged by the child's level and age because of the various needs of different age groups. The possible association between goals and expectations was considered.

*Device breakdowns.* Three families discussed device instability, breakdowns, and use of loaner devices during repair. Families reported different situations among device breakdowns and divergences between support during device problems.

Device breakdowns occurred with London, Zachary, and Elaina. Zachary stated "yeah, we've had too many, in the course of the time that we've had it; it's broken too many times. I can't quantify how many too many is." Parents elaborated on how device breakdowns affected their child and their child's behavior. All three described changes in their child's behavior, with either behavior challenges or anxiety and uncertainty. Elaina reported Jacob's behavior in the absence of the device:

He didn't get terribly upset. You could just tell that he was a little anxious because he would often walk to that, the location where it is at the house, and then just wander around. Or look around like, my device isn't there- what do I do now? (Personal Interview, January 13, 2011)

Jacob showed anxiety and uncertainty when his device wasn't there. Elaina described that if he saw her when he went to the central location where the device was kept, he wouldn't get upset but use nonverbal communication to let



her know what he wanted. Elaina described frustrations without the device as “it was frustrating to me 'cause I wanted to be able to him just tell me which one he wants.”

London described changes in behavior with Alice when her device was down or broken. In contrast to Jacob, Alice had behavior challenges that resurfaced when she was unable to successfully communicate. London also described Alice’s level of frustration increased because she’s not understood:

She starts usin' gestures and unfortunately the behaviors start come back big time. She gets very frustrated. She throws things. She slams her body around. She, she will try to do things herself and we don't understand what's goin' on. It's VERY frustrating without her device. (Personal Interview, December 28, 2012)

Alice and Kennedy were described as having behavior challenges when their devices are not working properly. Without the consistency of the device, they rely on previous methods of communicating, even if those methods were unsuccessful. The parents reported frustration as well because they could not understand what their child wanted.

In addition to device breakdowns, parents also reported device instability. All three parents who reported device breakdowns had dealt with a screen problem of some sort. London and Zachary described several troubleshooting methods before they determined if they needed to send it in for repair. Contrasting London and Zachary, Elaina described her device problem and how the private school speech pathologist completed troubleshooting, called technical support, and fixed the device for her.

London and Zachary had both been issued loaner devices a number of times. While London described this process was fairly simple for her, Zachary described that these situations fluctuated between “seamless” to a situation described as “frustrating to her. You could tell because it just didn't look right.” Zachary also stated how it affected the family “And we'd have to watch her from picking it up and trying to smack it down on the table.”

The loaner situation was made easier for London because of her relationship with the school augmentative specialist. London stated that the augmentative specialist would loan her a device while waiting for the loaner or go and get her a loaner device. However, if any time lapsed between devices, London reported Alice's behavior challenges started up again.

London and Zachary both mentioned a backup device. While London purchased an iPod for Alice to communicate with, London described Alice's preference for one device over another when she said, “she doesn't like the Proloqoe2go as much as I was hopin' she would.” Zachary also mentioned the affordances of using an iPad for Kennedy's communication. Besides the physical differences, he described the importance of consistency in her communication without breakdowns and how an iPad could facilitate smoother transitions:

But obviously with that being a \$7000 device we can't have a backup here for her when it breaks. It has to be shipped back to the manufacturer and we don't have a loaner tomorrow then we don't have one that we can pull out of the closet and immediately give her her voice back. (Personal Interview, January 13, 2012)

It was apparent through the conversation how important device accessibility and consistency is to Zachary and his family. Zachary described Kennedy's device as her voice as he mentioned that they needed to give her her voice back.

Three of the six families reported device problems, such as device instability, device breakdowns, and the use of loaner devices. During device problems, parents recognized negative changes in their child's behaviors. Parents described periods of device breakdowns as frustrating, not only for their child but for themselves as well. The use of a backup device was considered by one family and used by another.

*Duality of Device Use.* Devices were used within families in two ways: a technical way and a functional way. The technical device use included programming, hiding and showing buttons, and becoming familiar with the device. Some of the functional ways devices were used are for exploration, requesting, socializing, social interactions, and modeling. The technical device use lends itself to the functional use of the device by becoming familiar.

Five parents reported programming the device. Four parents reported the use of hiding and showing buttons at some capacity. London's perspective on her own device use was described as "Well if I'm going to expect her to use it, then I feel I need to know I need to know what's there." Moira described programming she completed within the second interview week:

My daily ABA lady...she wanted to update most of those are reinforcers or motivators on that page and so she wanted to update those and so we took pictures and we put those on there and so we did that and then I did add a page for his TV shows or movies so now he'll like to select DVD

player. And once he selects DVD player now it opens up a new page and he can pick between Thomas and Chuggington. And I'm gonna add more to that as far as shows he likes to watch here so I guess I was proud of myself for doing that and gettin' that done. (Personal Interview, January 5, 2012)

Moira was able to complete programming during the week of the interview and described device use as down that week because her family got sick. However, she felt accomplished because of the upward device programming progress.

The second use of the device was the one most typically reported. The second device use was simply using the device in a variety of functional and exploratory ways. Children within this study used their devices in a variety of ways, such as for exploration, requesting, social interactions, and communications. Elaina and Moira discussed modeling with the device to encourage the child's communication and as a way to introduce new language, advocate the use of the device, or just provide opportunities.

The device use reported by parents indicated that families were using devices in two ways: to prepare to teach and then for functional and exploratory use for the child or adult. The preparing to teach use allowed the parents to become more familiar with the device, while the second use encouraged functional communication. The overall uses of the device add to the complexity of device use as parents explained how they use the two device uses to increase communication through SGDs.

*Changes in Device Use.* Each parent talked about a change in device use over the period that they had been using the device. There were two different

kinds of changes in device use that parents talked about: a regression in device use and a progression in device use. A progression in device use was spurred on by a regression in device use (and therefore increased attention to facilitating use by parents or professionals) or an introduction of some sort, such as beginning ABA or private speech therapy.

The first change in device use is a regression in device use for children. Elaina described a period of regression with Jacob's device use where Jacob wasn't paying attention and or discriminating between buttons on his device:

He did have a period of time back probably would have been in November where he seemed to think the device suddenly had a magic button effect.

And he would hit anything, to get what he wanted, like he wasn't paying attention suddenly." (Personal Interview, January 5, 2012)

He did recover from this regression because of the insightfulness of Elaina and the school worked with him to remove buttons from the device and consistently continued to increase the language and buttons on his device until he was using his device typically again.

So since then, they actually took some of them away at that time made sure he was really, really accurate with the ones he had. Now they've built all the ones that were on there before back in and I think they had talked about once, he had his accuracy where it used to be, and I think it is now, then they were going to start working on more core vocabulary and some verb/noun combinations. (Personal Interview, January 5, 2012)

Some of these regressions were due to changes, such as Kennedy changing schools. Zachary described Kennedy's transitions "Actually she had a

lot of transitions, home therapist changed (pauses) she had a school change, she had a new bus route. She started a new program and so she had a hard summer with all the changes this past summer.”

Moira talked about a change in device use that increased Jefferson’s independence. Jefferson became more independent with his device because his ABA therapist included it in their routine.

And I would say in the last ...three to four months, he’s picked up on, I’m, I can, I can carry this and I can do this and do that and a lot of that is related to when we initiated our ABA and they made that part of his routine. (Personal Interview, January 5, 2012)

London was able to use Alice’s language plateau to increase her skills through introducing a new, private speech therapist. London described the speech therapist, “she knows how to use it to increase Alice’s language and she did she, she started Alice using making comments and having conversations skills and social scripts.”

Another progression in device use was described by Nadine. McKinley’s transition into a home and hospital program while searching for a new school increased his device use. Nadine reported: “...has progressed TREMENDOUSLY since being on home and hospital and me being around to supervise his speech/language and using his Aug comm.”

All of the parents described a change in device use over time. Some of the parents described that their child had regressed with device use during a particular period of time. Some of the changes occurred with understanding of the parent as to why the change occurred, such as Kennedy’s change in device

use. However, changes in device use or lack of positive changes in device use were not always understood by the parents, such as a language plateau Alice had; London did not know a reason that Alice hit a plateau with her language on her device. Positive changes in device use occurred as well. Within this study, parents described periods of regression and progression within device use for their child.

Parents' descriptions of their experiences with SGD use within the home facilitated the emerging theme of the complexity of SGDs as tools for communication. Parents described a difference in SGD use between themselves and their spouse. Parental goals added to the complexity of SGDs through the tension between the expectation and goal of SGD use. The duality of the use of SGDs also added to the complexity of device use because of the variety of ways the device can be used. Device breakdowns added complexity of device use because behavior challenges resurfaced and frustrations increased within the family. Within this study, the complexity of SGDs as tools of communication for children with autism emerged.

#### *Tension between Structure and Play*

The second super-ordinate theme that emerged was tension between structure and play with the device. The definition of play includes an exploration and learning of the world through sensory repetition (Brodin, 2005). Because children with autism have a deficit in the area of play (CDC, n.d.; American Psychiatric Association, APA, 2000), the use of speech generating devices within play can be more challenging and continuing to allow more structure may feel more comfortable for families. All of the parents described that their child was

driven by sensory needs, had not developed typical play skills such as symbolic play, and were motivated by food, drinks, movies, or other tangible items.

Parents had difficulty finding toys that engage their child. Moira talked about how play with her son involved creativity so that she can engage him with a toy.

That's a problem with being not interested in a lot of toys. He doesn't have interest in toys. His motivators are eating and drinking and tickles and TV shows. You know, so it's often hard to find the right way to interact with the talker, too so and just trying to find those creativity areas. (Personal Interview, December 29, 2011)

Once parents did find a toy that engages their child, then the creativity that Moira talked about comes into effect to figure out how to create scenarios where the parent can interact with the child and include SGDs in that interaction.

We have a learning Leapfrog train that goes in a figure eight pattern. And he wants that train to go. And so, we initially just started doing "stop" and "go" and we would stop it and we would model "oop, train stops" and then he would look at it he'd push "go." So that was kind of how we did that. And then, we added, now we have the stop and go, we've added "play" and "more go" or "more train" and then model "we like that." So, that's just like one thing I know like we have a toy that would work well with some of the core words that we wanted to do and then we go there I think that's a component. (Personal Interview, January 5, 2012)

Teaching play within structured times involved forethought on the adult's part as Moira pointed out. Caroline also talked about the therapist's job within playing a game with Tristan. This was what playing a game looks like for Tristan.



He will say "play." They will set it up to what options may be available in the therapy room like the Connect 4 or Hungry Hippos or Across the Top, whatever and they'll say "Tristan, what do you want to play?" and then he'll say- they might hide all of the other buttons and then he would say "play, expand, Connect 4" to make a choice for what he wanted to play with. He could spontaneously request, I don't think he does very often. He could spontaneously request to play one of these items as well, but right now it's still pretty structured. (Personal Interview, December 12 2011)

So, even within a break time from structure when Tristan has an opportunity to play a game, there still appeared to be a need for structure to hide buttons in order to allow him to make a choice. Caroline also added that he could spontaneously request these games at any time, but she doesn't think that he did that often. Due to the characteristics of autism, there may be a need for structure in order to facilitate Tristan's play using a SGD.

The notion of hiding and showing buttons was an important aspect of SGDs for families and was talked about with five of the six parents. There was a variety of ways hiding and showing buttons was used within different families. Hiding was used within teaching settings to work on particular words or skills. Nadine said, "Everything is always at home open. It is only what we're working on target vocabulary do we hide the other buttons." Nadine also stated that outside of teaching specific words, they allowed the device to be open in the home. Parents also used hiding and showing to hide a button if a child was perseverating on a particular word. So, sometimes, Moira said they needed to hide a word because Jefferson continually asked for something.

Moira: Sometimes Jefferson gets stuck in a motor plan. Like "more tickle" (laughs) that's all he wants. (R laughs) and if it's not appropriate for tickling, then I'll hide tickle. You know, he doesn't get to choose that. That sounds kinda mean, but he has, you know if we need him to be doing something else then I'll hide tickle. But he's smart and he realizes tickle under his ABA page and he'll go find it there.

Interviewer: (laughs) and so what happens in that kind of situation?

Moira: well, then he gets tickled. (Interviewer laughs) We get, he gets tickled because then you're like, "oh my geez the kid worked so hard, you know?" We do tickle him and but then just try and say, I might model like "oop, have to to stop or all done with tickles time to eat." (Personal Interview, December 29, 2011)

Moira showed us how this tension between structure and play happened when they hid tickles, but Jefferson accessed tickles on another page. This was an opportunity where Moira felt that even though she was trying to structure the situation, Jefferson's diligence outweighed that and allowed this play opportunity. Hiding and showing was also used as a way to prompt the child with what the parent may be trying to get him or her to select, such as when Tristan wanted to watch a show, but was getting upset. Caroline would hide other buttons to increase his success and decrease the chances that he would engage in negative behavior.

So I'd take the device over to him and I hide. When I notice that he's having behavior, I hide all the buttons except for the ones that I want him to push because if he hits a if he hits a wrong button during that time, I

know that he's going to start punching himself in the face. I made sure that he was gonna hit. And I knew he wanted to watch a show I could just, it was just an opportunity that you knew that. And so I hid all the buttons and he said "want to watch a video" and I would say "what video?" and he, his options were open and he would select Yo *Gabba Gabba!* Or whatever TV show he wanted to watch. So and then we were able to turn on the, we would turn on the video and we were able to avoid that behavior incident because he was able to request what show he wanted to watch appropriately instead of with self-injury. (Personal Interview, December 12, 2011)

Tension existed within this situation because of the possibility that Tristan may hurt himself if he selected the wrong item. Because Caroline didn't want him to engage in self-injurious behaviors, she structured the situation to make him successful. Tristan's device use allowed him to be able to request TV shows without engaging in negative behaviors as a way of communicating. Because Caroline was able to hide and show buttons within the device, they were able to avoid Tristan's self-injurious behavior.

Another way that tension was exhibited between structure and play was the notion that once the child had requested an item or activity so many times; the parents allowed the child to play instead of continuing to get him to use his device. Elaina talked about an instance where she or an aide may do this.

They're just like little animals he likes- he's really into zoo animals and farm animals and we'll only give him one. Well, he wants to group them all together and line them up, so he'll have to ask for another one. And then,

once he's doing a really good job, like, once he's done it four or five times, we usually start giving him two. Like, ok, he's getting this. He knows exactly what this gets him. And then, once he's gotten all of them, or as many as he wants, we just let him play with them. We set the talker over to the side, and he can ask for something if he wants but he did a good job of manding for that particular item. (Personal Interview, January 13, 2011)

So, they allow Jacob to play instead of having him continue to communicate throughout his playtime. This situation may be similar to a typical child whose parent corrects their language most of the time, but sometimes chooses not to in order to give the child a break.

The super-ordinate theme of tension between structure and play emerged through the parents' descriptions of structured play times and how they were able to engage their child in play. Parents talked about the structure within play and how they incorporated hiding and showing buttons to facilitate play with their child. Parents also described times when they allowed their child to simply play without the use of the device.

#### *Interplay between Requesting and Social Interactions*

Children who have autism have increased language to request items through the use of SGDs (Olive et al., 2007). Success socially interacting with familiar people comes easier for children with autism than interacting with unfamiliar people (Valiquette et al., 2010). For example, SGD use among children with autism increased social interactions within the classroom setting (Schepis et al., 1998). However, within the home, parents reported a spectrum of uses with SGD use and social interactions with family members. Thunberg and

colleagues (2007) report parents sitting closer to children with autism when using SGDs, while Marshall and Goldbart (2008) described a special parent-child bond that may decrease device use within the home for children with disabilities. The interplay between requesting language and social interactions will be discussed.

The children with autism in this study are socially interacting on some sort of level through shared joint attention, such as eye contact, shared focus, or initiating social communication. Nadine explained how McKinley used his device, which she referred to as his voice, to request an item:

So he will actually bring it without, we don't always have to say "go get your voice," he will get his voice and he will bring it to me. (Pauses) and its funny because sometimes he will when he brings his voice, and he goes through the pages, it will he will sometimes will hit wrong buttons, but he'll keep going. So he doesn't look at me, he doesn't make eye contact with me until if he makes a mistake, he'll go, go, go 'til he gets to what he wants and then, he'll hit it, and you know that's the one he wants because he immediately, big eyes looks up at ya and goes that's it. (Personal Interview, January 3, 2012)

The social interaction Nadine described allowed her to connect with McKinley through eye contact and understand what he wanted. The relationship between social interactions and requesting is complex.

There are times parents interact with their child without using the device. Three parents commented about specific social interactions within intimate family interactions when the device is not used. Parents wanted social interaction and

social communication. Nadine described family time when her oldest daughter came home to visit:

I don't know that we used it as much on the weekend as we did during the week because big sister was here with her husband. So he was just more in tune to them being here...so it was...more personal interaction versus using his device (Personal Interview, January 3, 2012)

Elaina shared a similar description of one on one time with Jacob as it related to device use: "it is sometimes, his one-on-one time with me is that we're just snuggled on the couch. So it doesn't get a lot of use then." Personal family interactions did not always require device use.

Unfamiliar social interaction does not come as easily for children with autism (Valiquette et al., 2010). An example of this is Zachary's description of Kennedy's lack of social interaction with other children and his feelings about the stigma of a SGD to her social interaction:

I don't think she cares about the stigmatizing piece of it. She doesn't care that people look at her strangely when she is wearing this big device around her neck, but it would facilitate some social interaction. We'd hope that she had something that was considered cool by the other kids, that other kids might be more, more interested and less scared off by her.

(Personal Interview, January 13, 2012).

He goes on to say "The one time that she has responded to (pauses) attention from another kid like that, her responses was 'Goodbye!' That made it pretty clear that she didn't want to play."

All of the children with autism in this study used their devices to communicate wants and needs through requesting behavior. During requesting, the children typically focused their use of SGDs on fulfilling wants or needs.

Elaina talked about Jacob's use of his device to request a snack:

He thinks it's time to eat again as soon as he gets home. So, usually, he'll immediately make use of the device, ask for a snack or a juice box or something. And then, he sits down and has some chill out time and he has a snack. (Personal Interview, January 5, 2012)

After Jacob receives his snack, he goes, sits down, and eats his snack. There's not much interaction going on after the request is made and he receives what he wants. Nadine described a similar situation:

It's more to tell me if a CD is over, tell me he wants a CD. Or a DVD. I should say DVD. Drinks, snacks, just like, a little bit ago you know, he brought his voice TO ME to tell me that the DVD was over. And that he wanted another one. (Personal Interview, January 3, 2012)

Requesting behavior appeared to contrast with social communication and interaction because the child seemed more focused on receiving the item than interaction. McKinley wanted his mom to change the DVD for him so he could continue watching shows or movies. London described a situation where this occurs with Alice trying to get access to an item and not necessarily concerned with social communication:

She's at the point now that she will go get her talker and when you see it (laughs) we all kind of say "oop, she's comin' towards you with the talker. She's gonna want something." (Laughs). (R laughs) She just finds us out.

Whoever she gets to first with the talker is usually who satisfies her needs.  
(Personal Interview, December, 28, 2011).

Two parents reported the use of devices for social communication. Moira talked about Jefferson's trip to see Santa "and he told Santa 'hi'". London talked about how Alice used her device at church:

And then after the services are over, she goes around on her own and talks to people. She goes "hi, how are you?" If they don't know her name, she'll say "My name is Alice Brown." Then she goes to the old ladies of course and asks to smell their hair. (R laughs) And then she'll, then she'll, she really good at sayin' "goodbye, have a nice day" that kind of thing on her talker. (Personal Interview, December 28, 2011)

London talked about the process of teaching Alice how to socially communicate after church and how it took a long time for her to be able to independently go around and talk to others on her device. Other parents, such as Nadine, mentioned that their child was not ready to socially communicate using the device yet.

Parents described use of devices to socially interact while communicating instead of purely for socially communicating. Four parents reported one or more occasions where it was evident that their son or daughter was socially interacting while using SGDs. Jefferson initiated tickles with his mom during the interview.

Moira: (To Jefferson) tickles? (To Interviewer) did you hear what- he just asked for tickles (laughs)

Jefferson: tickles

Interviewer: No... did he?!?



Moira: Yep, he just picked it up, gave it to me, and he said tickles

(Interviewer laughs)

Moira: (to Jefferson) tickles?? You want tickles? Ok buddy! (Playing with Jefferson) (Personal Interview, January 5, 2012)

This example shows social interaction with device use for social communication.

Another example Caroline shared where Tristan socially interacted and communicated with his device is as follows:

This week I remember it was again with *Fresh Beat Band* and we were, we asked Tristan "What do you want to watch?" and Michael said to me Tristan mumbled some sounds and Michael said "Man it sounds like he said *Fresh Beat Band* or he was trying to sound out *Fresh Beat Band*." And Tristan picked up his words and "Want watch video *Fresh Beat Band*." Now, I don't know if he really (chuckles) was trying to mouth it and then he used the device or if he just hit *Fresh Beat Band* because he heard dad say *Fresh Beat Band*. But I still thought it was great that he put that together. And that, I thought it was interesting that Michael heard him mumble and thought it sounded like *Fresh Beat Band*. And then he picked up his words and used his device to say *Fresh Beat Band*. (Personal Interview, December 20, 2012)

This was an opportunity Michael took advantage of to respond to what he thought Tristan was saying. After responding, Tristan used his device to solidify that he wanted to watch *Fresh Beat Band*. This interaction also showed Tristan taking simple conversational turns with his dad.

However, on some occasions, device use was able to combine interactions with requesting. Moira shared an interaction that occurred during the Christmas holiday that combined device requesting with interactions. Jefferson, Jefferson's brothers, and two cousins played and modeled on the device together.

Then they were all requesting more tickles from my husband and it was a great big game and the talker was involved and so then there was my three sons and then two cousins all wanting to be tickled and lots of it being pushed through the talker. (Personal Interview, December 29, 2011)

All of the children with autism that use SGDs in this study used their device to communicate their wants and needs. They also all socially interacted on a continuum of levels. Some examples of the social interaction from the children included sharing brief joint attention or eye contact, initiating social interaction to request something, or sharing physical contact for cuddles or tickles. However, only two of the six parents described situations in which the device was used for social communication. Parents also described times when they were socially interacting with their child without using the device. An example of this is when McKinley's sister came to visit and Nadine described family interactions as "personal interaction versus using his device."

### *The Fluctuating Role of Parent Advocates*

The fourth super-ordinate theme is the fluctuating role of parent advocates. Parents advocated for their child in a variety of ways and settings. First, parents advocated ensuring their son or daughter had a way to communicate and had access to their device. Parents also played an advocacy

role within the school setting or among private therapists. In addition, parents advocated for their child within the family and friends. The roles of parents in advocacy fluctuate depending on their child's situation. London shared an example of this with previous speech therapists:

The ones I've been to in the past, have always had me there in the sessions and they ask ME where's this on the device they're not familiar. I mean, they're not very familiar with the devices at all. (Personal Interview, January 4, 2012)

Parents advocated to make sure their child had a way to communicate. Moira shared this during the first interview: "his ability to get his needs met were, were struggling and plus, we got more aggressively pursuing ways to help him get that done." Nadine also talked about the importance of securing a communication system for her son, regardless of what it looked like:

Do I think that McKinley will ever verbalize? I, you know what; I really could care less whether he verbalizes. As long as he has a way to communicate to people, I'm happy. If it's via the Aug comm or sign language or any other form as long as he can communicate what he wants...that's all that matters to me. (Personal Interview, January 19, 2012)

Moira also talked about how important it was to give her son a way to communicate.

Sometimes you get this impression of somebody like "oh you've given up. Your kid's never gonna talk" like "Heck, no, if this kid talks, fine. We'll donate this device!" (Laughs) Whatever but at the same time, he still has

to, need to find a way for him so and I think sometimes people come up like "Well, I'm not ready to give up on that he's not gonna talk" I'm like "neither have I!" I said "but in the meantime, I have to have him a way to communicate" (Personal Interview, January 5, 2012)

Zachary also advocated not only for Kennedy to have a speech generating device, but for her to have continuous access to it.

And I think we communicated that to them. That we don't see it as a learning support tool that can be used here or there, we do see it as her voice. And so it has to be on her as much as a, the voice of a typical developing child, which is constantly...it always has to be available to her. But since we got over that hump, they always have it with her. Both in direct educational opportunities when she's doing one-to-one instruction, and when she's going to the gym or other places in the school. She has it with her and is using it all day long. (Personal Interview, January 13, 2012)

These parents wanted to make sure their child would have a way to communicate. Zachary even talks about making sure Kennedy has access to her device in case there is something she wants to communicate at any time. Three parents call the device their child's *voice* and Zachary felt that access should be equal to the access a typically developing child would have to their voice- which is always!

Parents were advocates within the school or private speech therapy setting, as well as with family and friends. Zachary advocated device use when he described nonuse of the device as: "we try to, we try to avoid that." and went on to share the importance of Kennedy having access to her voice at all times.

There were times when the school was letting her leave it behind and they were they were doing the thing which aggravates me absolutely more than anything else- putting it in her backpack. The idea to me that you let a child LEAVE their voice in the classroom while you go somewhere else. Also, that you would take a child's voice and stick it in their backpack. It's just upsetting to me. (Personal Interview, January 13, 2012)

The role of advocacy within the schools also was important. Moira began our conversation about school with: "we live in a rural area so this is their first experience with the Vantage Lite." She then went on to talk about how she advocates for the use of Jefferson's device with school:

And then, at school, they've had NO prior experience with a speech generating device and I think that's where you might see this. Where he is making a selection and not not having that connection with an adult or peer and then that people get upset well at the same time, is that it that truly Jefferson's problem? Or is that, as a mother, I would, I often think could that not be a symptom of well, well is everybody trained? And is everybody on the same page how, how's everybody trained? And is everybody on the same page? Of what we should not, doesn't have to be same page, same line, same paragraph, but you know this is how we're gonna try and have Jefferson initiate conversations and I have a problem with that! As a family managing all these different therapists and stuff. And if I'm not present then I can only I can only wonder what occurs (laughs) 'cause he can't come home and tell me. (Personal Interview, January, 5, 2012)

Moira advocated for Jefferson's device use at school and talks about how school is not well trained. Because Jefferson is not able to come home and talk about his school day, she found it even more important to have open communication and align the school and private therapies with home. She also advocated Jefferson's device use within his ABA therapy because this was another area besides school that wants to return to picture exchange.

And then, we started our ABA world because of just all the research that says you need to be getting this done he has made progress in there but they have different opinions about how he should have language and they are pretty, they're pretty. They can be strongly opposite. Sometimes and that was that's hard to figure out what to do as a parent and how to figure out what choices do we make and I think being able to reflect on this with you and give you some of our background and ideas, I guess I still feel good about where we're at versus trying to give up. I mean, I have a therapist saying "you know what? I don't think he's, the intent isn't there. He's not making the intent and give me 30 days with PECS and I'll get him talking" and that's what she tells me. And I'm like "WOW! That's great, that you just tell me 30 days and you'll get him to talk." (Personal Interview, January, 5, 2012)

Moira discussed some of the concerns of being a parent of a child who has autism and doesn't have verbal language. Between school and ABA, Moira is receiving a lot of different advice about the way her son should communicate. However, even though she described the ABA therapist as wanting to switch to picture exchange, Moira later described being proud of herself for the headway

she has made with Jefferson's ABA therapist. Moira said she had the therapist consider device use:

And then, in the ABA world, we've talked about that you know, they're ...they're, they're very big at moving to PECS and I've possibly got them willing to consider using the device instead. And so they're trying to incorporate some trials to of, with the device to drive what they think needs to happen next as far as his skills and so forth. (Pause) So in a specific nature, I mean like, I think ...with his ABA interventionist, he is saying hello to her when she comes, you know. He's not seeking out the talker, but if she brings it to him he says "hi" you know. And that's melting her heart, she loves it. And (laughs) and he's requesting break time and she loves that...and um...I think she's seeing him make more purposeful requests. (Personal Interview, January 5, 2012)

Moira described advocating device use with her ABA therapist and the tensions that are a part of that relationship. However, because the ABA therapist is seeing Jefferson is capable of using the device, Moira feels that she is becoming more open to using it with him.

London and Elaina described a different advocacy role that they have played in the past with private speech therapists. London described previous speech pathologists' knowledge and use of SGDs as unfamiliar and unknowledgeable. Elaina described her advocacy role with a previous private speech therapist:

So she had used some of the simple there were only like six buttons, I don't even know what it was called. Just in her speech therapy session,

but that was just I actually, once he started making good use of the Vantage, asked her to not do that so that he wouldn't it wouldn't mess with his motor planning for the Vantage. (Personal Interview, January 5, 2012)

Elaina felt strongly that the Vantage was the device her son should be using and eventually stopped the private therapist from using other devices. As an advocate for Jacob, she took the role of asserting her confidence in the use of one device for her son.

Elaina's role as an advocate was different than the other parents in that Elaina did not appear to have a need to advocate as much with the school because Jacob attended a private school that mom seemed pleased with. She describes daily communication within the school classroom staff and emailing and weekly conversations with the private therapists. She goes on to describe her relationship with the private speech therapists:

But if there's ever any concern whatsoever, I email them immediately and they're both very quick to respond. There have been times when somehow he'll hit a button and mask everything and in the past, I just text Mia if I can't figure out (laughing) how to fix it. And she texts me back and then I say "ok, I'll save this text so I don't ever have to ask you again." And then I forget to save it, and I have to do it again but we have VERY open communication. I am very involved with the school, so which the communication is great back and forth. And I, I almost think it would have to be so that I can know how they're growing with him at school with it so we can try to I mean, they're definitely better at it at school than we are at home. (Personal Interview, January 5, 2012)



Elaina's advocacy role also was evident through her involvement and observation in a variety of settings Jacob used his device in, such as school and church. In addition, Elaina's advocacy was clear with Jacob's grandparents because Elaina wanted him to use his device to communicate.

I have to usually say to them "Hey mom. Get him to use his talker "and they immediately will "OH! Yeah, yeah! Jacob, Jacob comes here! Come here!" They take him to it. You know whatever, but then yeah they're really excited when he uses it. "Oh yeah! He wanted pretzels. Oh yeah, okay, let's go, let's go!!!" (Personal Interview, January 13, 2012)

Parents played an advocacy role outside of school as well. Nadine explained her role in the explanation of McKinley's device "Well, okay, with McKinley, it is his voice. That's his voice. And so we call it what it is." She also described how she advocated for McKinley within her family and friends network. She described the process of sharing McKinley's success stories as "telling what he CAN do." Nadine went on to share a success story:

I tell them usually of his success stories, of (laughs) I just told my husband the other day when he got the DVD and wrote, typed in "I like that" just constant success. "Look what McKinley did. McKinley did this. McKinley did that." (Personal Interview, January 3, 2012)

Caroline's role of advocacy also fell within the home as she advocated device use and device education with her husband. Caroline shared an experience where she coached Michael through making a technical change on the device.

We kinda had an experience this week where I coached him through it.

You know, he was, we knew Tristan was wantin' something that wasn't on there. And I said "Okay Michael, how do you change it? You know we need to put that button on there. - How do you change it?" (Personal Interview, December 20, 2011)

The purpose of Caroline's advocacy was to assist her husband in becoming more familiar with hiding and showing buttons. Nadine also talked about a previous advocacy role within her immediate family.

I think the hardest thing has always been. When he was going to school, and his device would go to school with him and then come home in the afternoon, was getting my family to understand how important it was to make his device available to him 100% of the time. So I had the routine down, but you know when he came home, I unpacked his bookbag got his device out, opened it up, made sure it was you know on the right setting. Asked him "What do you want?" Use your voice; tell me what you want to drink for snack." And he would do that MOST of my kids When I started school, I wasn't home one day a week and so they would just leave his device in his bookbag and go get him his pretzels because he always asked for pretzels. (Laughs) And so I had to really get on everyone and say "now it needs he may want popcorn today. You know, he may just change his mind. He may surprise you. Get it out. Let him use it. And if he asks for pretzels, give him pretzels. If he asks for popcorn, give him popcorn. That's going to be his voice and that was kind of the hardest thing was even with my husband, was getting them to see that this was

not a toy. That this was going to be the way that McKinley communicates.

(Personal Interview, January 3, 2012)

Nadine needed to advocate for device use because family members were and selecting McKinley's snack based on his routine, instead of asking him what he wanted that day.

Advocacy roles for parents started with ensuring communication and device access. Parent advocacy roles fluctuated depending on the child's situation, such as after school transitions. Parents advocated within the schools and with private therapists. Parents also described previous advocacy roles within schools or private therapies. Not only did they advocate within the schools and with private therapists, but parents also advocated within their families and friends.

#### *Building a Diverse Support Network*

The final super-ordinate theme emerged regarding family support systems. Each parent has built a support network for device use with his or her child. Each of these support networks looked a little different and functioned a little differently. Support networks included some or all of the following: immediate family members, extended family members, aides, school staff, augmentative specialists, school speech pathologists, and private speech pathologists, and private therapists.

*Family support networks.* Diverse support networks began from within the immediate family. Zachary described a "division of labor" within the family as the following "Kennedy and I go in one direction and my wife and George go in another direction for the great majority of our our time because the two of them

together just really doesn't work.” However, Zachary described his wife, Cindy as sharing the role with him, except due to the “division of labor,” Cindy spends less time with Kennedy and has less opportunities.

So her mom, same as she does of me and so I don't think it would vary much from and I know that the ride into school experience. (Laughing) The language is pretty similar to the ride home one that I described. So I don't think it's that much different. It's just with the family division of labor that I described, she spends more time with me, but she uses the talker the same with my wife as she does myself. (Personal Interview, January 13, 2012)

Another example of support networks within the immediate family is the shared responsibilities that Moira reported between her and her husband. Moira's husband is a part of Moira's network of support. Moira reported that her husband is supportive and assistive with the device as she described her family trip to the museum:

I think that I was happy my husband was taking an effort. A good. He said "I'll take the talker" you know. At the museum, he was wearing it and was ready to you know, go explore this museum with his son. (Personal Interview, December 29, 2011)

She went on to say that her role is larger with device responsibility; however, she does not attribute that to the device, just being a mom.

I wouldn't necessarily assign it to the talker per say but I mean, I'm the one that's like "Okay, what we need to get out of the house? You know you have 3 kids what do we need to get out of this house?" You know and

so I'm the one that you know in charge of remembering this, this, and this talker falls underneath that umbrella. (Personal Interview, December 29, 2011)

Moira went on and explained how her husband's device use looked different from her device use. She described the differences in device use as if just another part of differences between what she as a mom does versus what her husband as a dad does.

My husband might be, he likes you know, kinda do these novel times where he's gonna interact. And he has that time 'cause Jefferson wants to see him. And be with him for these tickles or whatever they're gonna do. Which is usually tickle. That is a good way for that to happen. And for me, I'm just trying to manage the kids all DAY, and so, and then I incorporate the talker into that management process. (Personal Interview, December 29, 2011)

Elaina's situation is unique in that she is a single mom. However, Elaina has built an extension of family support network through the aides that came into her home and helped with the boys. The aides were not related to Elaina, but offered support on a weekly basis as family members might.

Almost any time we are going out into the community, it's one of the aides with me. I can, there's a few things I can do with the boys by myself now, but not a lot because they are very limited in communication and Elijah my older son can sometimes have some behavior that requires my total attention. So any time we, it's either myself and one of my aides or myself and one of my girlfriends. But my best friend lives up here now. So well

she is one of the aides, but on her own time also, she will go with us to where ever we might go to an indoor playground or something. (Personal Interview, January 13, 2011)

Nadine expressed how the family got on board and described this as a recent change within the home. She also mentioned how it made her feel to have everyone's support "It's like FINALLY! (Laughs) (BOTH LAUGH)...I knew this was going to work. It, it's nice. It makes my life much easier. It makes everything more consistent for him. So yeah, life is good."

Family support networks were also built around siblings. Siblings within Moira and London's family systems played direct support roles within device use. Moira shared how her six-year old assisted her with Jefferson's device use.

I think my older son the six year old, Carter; he'll say things like "Mom you know what we should really put on the talker? We should put" you know, and he'll wanna put like some kind of toy on the talker or something like that and so, he understands that that's his voice and that's what he needs and so he'll say, he'll say (Laughs). He's very good at telling us "mom, his talker's not here." (Personal Interview, December 29, 2011)

London described her son's relationship with Alice "So he's pretty much a caregiver role more so than a sibling role." Both families that talked about siblings as part of the support network reported that the sibling's device role was similar to a care giving role. This is in line with the study findings about siblings growing up with a brother or sister with autism (Benderix & Sivberg, 2007).

The next support level is extended family. Three families reported extended family members offering support as part of a network of support for the

family. This may not be indicative of the support the other families receive from extended family members, but is representative of what the parents talked about within the semi-structured interviews.

Grandparents were involved and or supportive of device use within three families and each of these supports looked and functioned differently.

Grandparent roles ranged from an active and involved device use to supportive, but not involved to a more typical role of a grandparent as to spoil and enjoy the grandchild.

Elaina's parents fulfilled an active role with device use by supporting and using the device with Jacob. Moira reported a similar role with her parents, Jefferson's maternal grandparents. Moira shared that her father, Jefferson's grandfather, was attending a second training and wanted to gain access to the device software. Moira reported Jefferson's paternal grandparents as playing a supportive role in device use, but less active.

Grandmothers were noted to be part of Zachary's support system, but played a role more typically thought of by grandparents. Zachary explained both grandmothers' involvements with Kennedy's device use as possibly using the device less and following Kennedy's nonverbal communication "She wants to be a grandma and not a therapist & that's fair enough."

Along with grandparents as part of the extended family support network, Moira also discussed a few uncles' involvements and interaction with Jefferson utilizing the device. A specific example occurred over the Christmas holiday. Jefferson used his device with to socially interact with his uncle "he was traveling for it there as far as asking tickles from his uncle." In addition, Moira explained

another situation during the Christmas holiday where extended family members were part of the support network of device use for Jefferson.

Five families appeared to have built support networks within family friends, church, or familiar individuals. An example of this was reported by Caroline about an assistant that worked with Tristan at school. Caroline described how the assistant attended the same church that their family did and how she helped in his Sunday school class one week. Because of the assistant's familiarity with Tristan and his device, the assistant utilized his device within the Sunday school environment. "I'm thinking that's why they used the device is because Ms. Jessica was there. She knows he uses his words and she had the device out." Caroline reported device availability in Sunday school, but said Tristan typically did not use it.

*School support networks.* All of the children studied utilized the device in some capacity within the school day. Parents described children as using the device at school, but not of staff always being supportive of device use. Moira and Nadine both were unsupported by the school to the point that the school suggested that their sons were not ready for a SGD and or discussed changing communication systems back to picture exchange. Moira described the school's position "They want to go to a PECS communication system and ...you know that's something that I'm (pauses) I guess I'm not on board with."

London described that the school used the device with Alice, but the classroom staff was not very knowledgeable. Within London's school support network, she had an augmentative specialist that played a significant role in Alice's device use and support for London.



Communication between home and school was viewed as an important aspect of the school support network and varied as much as the support networks system. Caroline, Elaina, and London described school environment communication occurred through a variety of ways including in person, email, and phone. Elaina summed up the communication between home and school as a necessity: “I almost think it would have to be so that I can know how they're growing with him at school with it.” Zachary described the need for better communication within the classroom staff as a way to increase the support network, while he asserted confidence in the communication he received from the school speech therapist and behavior specialist.

*Private therapies.* The final support networks that were built encompassed private therapies. Four of the six parents reported their child currently received private speech therapy. Three parents reported their child received private ABA services.

Among the four parents who reported private speech therapy, all reported the therapists as important parts of a support network. Parents reported close relationships with the private speech therapist. Elaina even described her speech therapist who is on maternity leave as a friend. Nadine appeared to have a similar relationship with her private speech therapist as she reported sharing McKinley’s recent accomplishment with her: “Because I had told his speech therapist on Tuesday.”

Zachary mentioned Kennedy used to receive private speech therapy, but he didn’t elaborate on the therapy or the cause of its termination. However, London, whose daughter Alice was still receiving private speech therapy

described past speech therapists as unknowledgeable. Nadine explained the importance of a speech therapist on the child's device use: "unless you are blessed with a good speech pathologist, that is, that is very knowledgeable about the use of Aug comms, (pause) you're not gonna have the success stories."

Three of the parents reported private ABA therapy. Caroline and Zachary's descriptions verified the ABA therapists as part of their support networks through collaboration. Caroline described receiving advice from her ABA therapist for how to handle an aspect of Tristan's device use within the home. In contrast, Moira reported her support system with her ABA therapist as two-fold; she received support from her ABA therapist regarding Jefferson's device use, but also described this relationship as increasing Moira's uncertainty and doubt.

When you have therapists that are important in your life like 'cause they provide you a lot of support ways to do that and we, and this one's been our speech therapist and our occupational therapist in the cotreatments. They've been great for us and giving us a chance to give him language. And then, we started our ABA world because of just all the research that says you need to be getting this done. He has made progress in there, but they have different opinions about how he should have language and they are pretty they're pretty they can be strongly opposite. Sometimes and that was that's hard to figure out what to do as a parent and how to figure out what choices do we make and I think being able to reflect on this with you and give you some of our background and ideas, I guess I still feel good about where we're at versus trying to give up. I mean, I have a therapist

saying "you know what? I don't think he's, the intent isn't there. He's not making the intent and give me 30 days with PECS and I'll get him talking" and that's what she tells me. And I'm like "WOW! That's great, that you just tell me 30 days and you'll get him to talk." (Laughs) you know!?!"

(Personal Interview, January 5, 2012)

Moir's description showed how, as a parent, she felt uncertainty about the varying roles of the support network and how that affected her decisions and choices. The uncertainty of not knowing what to do or whose advice within her support system to use is an important aspect brought to light.

Each family reported building a support network for device use with their child. Support networks had a variety of family, friends, and professionals that work with the family and the child with autism. Each support network looks and functions a little differently, but allows the parent to gain support from others, as well as brainstorming and the continuation of device use.

### Summary

Five super-ordinate themes emerged through this qualitative study about family experiences with children who have autism and use speech generating devices. The first super-ordinate theme discussed was the complexity of SGDs as tools for communication. The complexity of SGDs was seen through the differences in parent use and setting goals for the child's device use. The duality of device use within how parents prepare the device to be utilized and then how the preparation affects the functional uses of the device increases the complexity of the use of SGDs. In addition, changes in device use over time increased

complexity of device use in order for parents to continue to see communication improvement with device use.

The second super-ordinate theme discussed was tension between structure and play, which was seen through the descriptions of a structured play to accommodate children with autism learning to play. Next, the third super-ordinate theme discussed the interplay between requesting and social interaction as these two sometimes work against each other in that a child requesting an item is not attempting to engage in a social interaction.

The fourth super-ordinate theme discussed the fluctuating role of the parent as the advocate depending on the needs of the child. The fifth and final super-ordinate theme discussed how parents built a diverse support network to facilitate use of the SGD within the family and home. Each of the support networks described was unique in which individuals were part of it and to what extent each individual played. Some of the supports reported included immediate and extended family members, as well as family friends, school, and private therapies.

## CHAPTER V

### FINDINGS AND INTERPRETATIONS

A large percentage of children with autism do not develop typical speech (Mirenda & Iacono, 2009), and speech generating devices have been deemed a useful intervention tool for these children (Schlosser & Blischak, 2001). This study was conducted to learn more about family experiences with autism and speech generating devices. This chapter first presents a summary of the findings, followed by conclusions and implications that emerged through the current study that might inform and provide suggestions for families who have a child with autism and professionals who work with children who have autism. Suggested areas of future research relating to autism and speech generating devices will also be discussed.

#### Summary of the Study

Research in the area of autism and speech generating devices has focused on children and youth in beginning stages of device use (Sigafoos et al., 2004; Trembath et al., 2009). Children with autism can learn to use speech generating device to communicate (Trembath et al., 2009), but what happens next? There is a gap in the literature between initial stages in device use with children and youth who have autism and have been using speech generating devices for a period of one year or more. Ongoing device use has not been well-documented and is an area of uncertainty. Research states that families who receive technology abandon use within the first year at rates of 30% (Johnson et al., 2006). With this being said, it is important to understand what family experiences have been and possible reasons for technology abandonment. This

study investigated family experiences with families who have a child with autism using a speech generating device. The research question that is posed is *What are the lived experiences of families with children with autism who use SGDs?*

The literature review stated families using SGDs become experts not only on the child using a SGD, but also on SGD use (Marshall & Goldbart, 2008). Families who were given input on their child's device use (Johnson et al., 2006) and who received support and collaboration are reported to continue technology use (Parette, Huer, & Brotherson, 2001). Children with autism who use speech generating devices increase communication in a variety of ways (Koppenhaver et al., 2001; Olive et al., 2007; Thunberg et al., 2007), increase social interactions (Schepis et al., 1998), and decrease challenging behavior (Choi et al., 2010).

Six parents volunteered to participate in two phone interviews about their family's experiences with autism and speech generating devices by responding to an email sent by the Center for Augmentative and Alternative Communication (AAC) & Autism. Participant criteria were as follows: a parent or caregiver of a child with autism under the age of twenty-one who has been using a speech generating device for a period of one year or longer and who resides in the United States.

### Findings and Conclusions

The participants in this study shared their stories and family experiences in order to assist others who are pursuing SGDs for their child, and also to generally share their stories as a way to teach and advocate for their child who has autism. Within this study, five super-ordinate themes emerged. The first theme is the complexity of SGDs as tools for communication. The second theme

is the tension between structure and play, followed by the interplay between requesting and social interactions. The fourth theme is the fluctuating role of parent advocates. The final theme that emerged within the study was the building of diverse support networks.

### *Discussion of the Complexity of Using Speech Generating Devices*

The first super-ordinate theme, the complexity of SGDs as tools for communication, brought a variety of topics to light. The complexity of SGDs was seen within differences in SGD use between parents. Of the five participants who were married, four expressed different roles within device responsibilities than their spouse. London described how her husband was “slow to use the device with her at first when she was younger, but now because (laughs) she’s used it ALL these years he, he knows to prompt her ‘I don’t know what you want.’” Zachary reported he and his wife have the same roles with device use and responsibility, but the frequency is different because of the “division of labor.” Parental goals added to the complexity of SGDs as tools for communication because parental goals may be associated to expectations of the device which may or may not be realistic. The duality of device use explained how the device is used as far as programming, hiding and showing buttons, etc. in preparation for how the device is used for communication. This type of device use also increased the complexity of SGD use because of uncertainty by parents and technical aspects of the device itself. Moira described her own uncertainty when she first used the device:

I think part of me, for the beginning of it, also fell into what I think some of our grandparents have is well, we don’t know what to do or what’s the right

way to use it is it like is there, oh, that could be WRONG, I just, I've come to like, you know, I don't know that it's so wrong you know, sometimes. It'll obviously- we'll find what works best for Jefferson. (Personal Interview, December 29, 2011).

Differences between device use among parents have not been studied in families with a child with autism. The professional literature has suggested that device goals be developed while considering family need without increasing their stress (Granlund et al., 2008). Further, goals should be a shared commitment (Angelo et al., 1995). Parents in this study shared personal goals for their child and their device use and each family collaborated with at least one support on their personal goal for their child.

Successful incorporation of SGDs into family life requires time and energy (Parette & Angelo, 1996). Management of a SGD can increase stress and loneliness for parents (Goldbart & Marshall, 2004; Marshall & Goldbart, 2008). Trainings increased the parents' results and sense of accomplishment (Adamson et al., 2010; Ronski et al., 2010). Parents in the current study put effort and energy into their child's device use; however none of the parents expressed stress or loneliness. Parents only expressed frustration within device breakdowns. Device use can increase independence and self-esteem (Brotherson et al., 1996) All of the parents described increases in independence for their child, while impact on self-esteem was less clear.

Device breakdowns increased the complexity of SGD use due to a number of factors including communication without device, behavior challenges, troubleshooting, and the use of loaner devices. Device breakdowns added to the



complexity of SGDs because parents reported their child's reliance on the device. During device breakdowns, parents reported behavior challenges or anxiety and the frustration of the child and parent. Zachary summed up device breakdowns for Kennedy when he stated, "We hate it!" Two of the three parents who had experienced device breakdowns reported importance of having a backup device available. Zachary reported that they wanted to "immediately give her her voice back." The final topic within device complexity is changes in device use over periods of device use longer than one year. All of the participants had seen at least one period of regression or progression in the amount of time their child had been communicating with a SGD. Sometimes, parents were uncertain of the cause of the regression or progression, such as Alice's language plateau. However, after introducing a new speech therapist, Alice progressed again.

Forty percent of devices broke down within the first year of use and within a five year period studied by Shepherd et al. (2009), 66% had broken down. Among the six participants in the current study, three have had device problems and or breakdowns within the last year. Device problems and breakdowns increased the level of difficulty for progress (Rackensperger et al., 2005). Parents in the current study only spoke about loss of short-term progress during device breakdowns. The literature reports that breakdowns can even lead to temporary abandonment (McNaughton et al., 2008). An example of this is Zachary's interest in switching over to the iPad due to the availability and ease of replacement. Changes in device use over periods of time were not documented for children with autism using SGDs.

### *Discussion of Tensions between Structure and Play*

The second super-ordinate theme of the tension between structure and play brought to light the convergences and divergences within use of the device to either structure the environment, play, or both. There was a notion of the need to hide and show buttons as a way to structure the device in order to stop a child's perseveration or increase success. Because of the nature of autism and the difficulty with engagement in toys (APA, 2000), tension existed between structured play and a free type of play. Caroline described this tension between structure and play for her son, Tristan with the following "he doesn't know how to do pretend play or he doesn't play with toys still appropriately. I mean we're still trying to we've taught him several but that's usually in a structured environment." Parents also described scenarios where their child has been requesting with the device and parents decreased device demand. Elaina described this after Jacob completed a manding session "And then, once he's gotten all of them, or as many as he wants, we just let him play with them."

Previous research described play for children with severe disabilities as something that was asleep that needed to be "woken up" (Brodin, 2005) because play is such a large part of childhood (Lane & Mistrett, 1996). These research studies speak to the fact that parents in the current study experienced tension between structure and play. Parents saw the need to facilitate play for their child; however, the very act of teaching play is a structured activity. Children with autism experience deficits in play skills (CDC, n.d.; APA, 2000) that make it more comfortable for them to forego play for structure. However, there were parents within this study that encouraged play with their child. Moira gave examples of

situations created for Jefferson's play, such as tickles with dad at night. A parent suggested playing games and modeling on the device for the child (McNaughton et al., 2008). Moira and Elaina also described playing and modeling on the device with their sons as away to show him they can use the device also and show him language.

Previous research reported play and exploration of SGDs as an important way for individuals using SGDs to learn (McNaughton et al., 2008; Rackensperger et al., 2005). Zachary and Nadine specifically discussed their child's exploration of the device and the importance of allowing them to play and learn. Nadine expressed that exploration had meaning for her son, while Zachary said device exploration facilitated better use of the SGD for his daughter.

However, for children with autism, play skills generally have to be specifically taught to them (Lantz, Nelson, & Loftin, 2004). This is where the tension between structure and play really begins to be seen. Children with autism are taught play skills within structured settings and then are supposed to generalize these skills into other settings and with other people. However, children with autism have difficulty generalizing skills and this may be a barrier to learning play skills and using them in a variety of settings (Sigafoos, O'Reilly et al., 2004). However, two research studies found that children with autism using SGDs to communicate generalized skills into new settings (Sigafoos, O'Reilly, Ganz, Lancioni, & Schlosser, 2005; Trembath et al., 2009). The tension between structure and play speaks to the difficulty generalizing into new settings. A specific example of the possible way this applies to the current research is how

Tristan is taught specific play skills, but doesn't utilize them outside of his structured ABA setting.

Naturalistic play is an intervention that increases skills for children with autism (Schepis et al., 1998). Parents described using naturalistic play to increase their child's motivation to communicate. Zachary described naturalistic teaching as a way to follow Kennedy's lead and promote SGD use within this play. Because of the overall importance of play to the parental bond (Lane and Mistrett, 1996), parents of children with autism sought a variety of ways to promote play and exploration with their child.

#### *Discussion of the Interplay among Requests and Social Interactions*

The third super-ordinate theme of the interplay between requesting and social interactions addresses another characteristic of autism- social interactions. Social interactions are typically difficult for children who have autism (APA, 2000). The children in this study were socially interacting with their parents, although this social interaction was delayed for their age. Parents described specific times where the device was not used for intimate social interactions. All of the children used their device for wants, needs, and things that motivated them. However, social communications were only described by two parents. The relationship between requesting and social interactions appeared to push and pull against each other because requesting only involved communication to ask for something; it doesn't easily allow for longer social interactions. Nadine described how McKinley would ask for a DVD (which he calls CD) when the DVD was finished. Once he received his DVD, he was done interacting.

The literature regarding children with autism who use SGDs to communicate reported SGDs increased social interactions through allowing the child to request items (Schepis et al., 1998; Sigafoos, Green, Payne, Son, O'Reilly, & Lancioni, 2009). However, in the current study, rich parent descriptions of device use show that when the child used the device to request, there was minimal social interaction due to the fact that the child was merely trying to gain access to an item or activity. The differences between the perceptions in previous research and the current research may be the importance of the quality of the interaction rather than the quantity of the interaction.

Research also reported decreases in challenging behavior through the use of SGDs (Sigafoos et al., 2009) which was similar to what parents reported. Thunberg et al. (2009) reported parents stayed in closer proximity to their child using a SGD. Parents in the current study did not make this claim, however, parents did report being in tune to device use in circumstances where the child may have made a request without gaining anyone's attention or when the child is physically further away.

Marshall and Goldbart (2008) reported parents of children with disabilities who were using SGDs to communicate spoke about a special bond with their child and the use of nonverbal communication which took away from device use. Parents within the current study appeared to be divergent from this approach of utilizing nonverbal communication instead of SGDs; they reported high levels of motivation to push their child to communicate. However, the parents did note

special times when they may not use the device for intimate interactions, such as immediate family gatherings, cuddling, or affection.

The majority of research on SGDs with children who have autism focuses on communication for requesting needs and wants (Chiang and Lin, 2008; Son et al., 2006). However, there is a multitude of pragmatics (i.e. descriptors, possession, existence, wh- words, etc.) required to continue language growth towards higher level communication such as simple turn taking in a conversation (Prizant et al, 2006). In this study, all parents reported their child used the device to request needs and wants, but only two parents described their child's device use for social communication purposes. Because of the emphasis parents expressed about the need for their child to be able to communicate, parents had a larger vision of what communication is than the child's present capabilities.

#### *Discussion of the Fluctuating Role of Parent Advocate*

The fourth super-ordinate theme is the fluctuating role of parent advocates. This group of parents strongly advocated both for their children and for the use of SGDs. Through the interviews, they shared how they see the world differently because of their experiences. The parents' roles in advocacy changed depending on their child's needs. Because Alice is about to complete high school, London's advocacy roles are geared towards planning for Alice's future, while Moira's focus is more on getting the school and ABA therapist to support her and use the device with Jefferson. Advocacy roles do not end with school or private therapy- parents also described advocating within family and friends, as well as in general for their child's communication and access to communication.

Parents of children with disabilities report advocacy roles as a critical part of being an expert on their child and their child's SGD use (Marshall & Goldbart, 2008; Valiquette et al., 2010). This study also found parents to be experts on their child and his/her SGD use, as well as their child's advocate. Parents also played the roles of programming the device and teaching their child how to use the device (Marshall & Goldbart, 2008; Valiquette et al., 2010). Similar practices were reported from parents participating in this study, with the exception of one parent who did not appear to do programming of any sort. Marshall and Goldbart (2008) reported parents who had a child with a disability that used a SGD described being pushy and finding their own way to help their child. Although parents in the current study described a support network, they also described similar situations of being pushy, finding their own way, or similar strategies to help their child.

#### *Discussion of Building Diverse Support Networks*

The fifth and final super-ordinate theme is building a diverse support network. Each parent described a support network of individuals that provide support in a variety of ways and levels. The five married parents described the spousal support role and two families also reported that siblings played a role in the support network. In addition, three families described extended family members as a part of their support network, along with family friends.

Diverse support networks included the schools the child attended, however the levels of support within the school network varied. All parents reported that their child used the device during the school day, regardless of any additional support from the school. Parents relied on private speech therapists

and ABA therapists as another aspect of their support network. Within the private therapies, families received various support. Parents also reported controversy within therapies that increased uncertainty and doubt. Moira described her ABA therapist and how important the support she received was, but she also described conflict within this support with the following words:

And then, we started our ABA world because of just all the research that says you need to be getting this done. He has made progress in there, but they have different opinions about how he should have language and they are pretty, they're pretty, they can be strongly opposite. Sometimes and that was- that's hard to figure out what to do as a parent and how to figure out what choices do we make. (Personal Interview, January 5, 2012)

Within this study, the super-ordinate theme of developing a support system was seen through relationships with a variety of people: family and friends, school, and private therapists. The need for a strong support system for parents of children with autism who use speech generating devices may foster ongoing device use. Parents who participated had a range of experiences with school systems, school speech pathologists, private speech pathologists, and other therapists and professionals. The need for collaboration and consistency within the school, private therapy, and home settings was important for increased proficiency and device use. Parents received various information and conflicting advice that left them in a state of confusion and doubt about the value of SGDs and how to incorporate SGDs in daily life.

Research that depicts support within families who have a child with autism report the mother's role as the most significant role (Gray, 2002). The maternal



role of caring for a child with autism became a full-time job for many mothers (Gray, 2002). Mothers raising an adolescent with autism spent more time in a care-giving role than mothers of a typically developing adolescent (Smith et al., 2010). Within the current study, the role of the mother was also larger than the role of the father in four of the five married couples. One married couple reported equal responsibilities with their child's device use.

Margetts et al. (2006) found that support from grandparents with a family who has a child with autism also indicated more received support from friends and others as well (Margetts et al., 2006). Two of the three families in this study reporting support from grandparents did also receive supports in other areas. However, a conclusion to this association cannot be made. Bayat (2007) reported some siblings of a brother or sister with autism described themselves as more caring and compassionate because of their brother or sister with autism. Within the current study, two of the three families with typical siblings were indeed caring and compassionate. However, more research needs to be completed in this area.

Speech pathologists within AAC were considered a part of a specialty field with a lack of professionals who were qualified (Rackensperger et al., 2005). Two of the parents described experiences similar to speech pathology as a specialty field. London shared her previous experiences with speech pathologists, "they're not very familiar with the devices at all." Goldbart and Marshall (2004) reported some parents felt lucky to have great support within speech therapists. Four parents from the current study received support from their speech pathologist and had built a special relationship with the speech pathologist. Professional

support was noted as important and parents had the most expectations of the child's speech pathologist for support within device use (Hetzroni, 2002). Even though four parents reported their child attended speech therapy, parents did not report expectations of the speech therapist.

Research associated lack of support for augmentative and alternative communication with technology abandonment (Johnson et al., 2006). An example of this in the current study is Moira's ABA therapist whose support was mixed between supporting device use and trying to get Moira to move to a picture exchange system; Moira mentions "trying to give up." Moira talked about the mixed support she was receiving:

I guess I still feel good about where we're at versus trying to give up. I mean, I have a therapist saying "You know what? I don't think he's, the intent isn't there. He's not making the intent and give me 30 days with PECS and I'll get him talking" and that's what she tells me. (Personal Interview, January 5, 2012)

Parents expressed frustration with the amount of support received (Goldbart & Marshall, 2004). Two parents within the current study expressed frustration within support received. One of the most important ways to facilitate SGD use was through collaboration (Stephenson & Dowrick, 2005).

#### Implications for Practice and Future Research

The current study focused on the experiences of families who have a child with autism who uses a speech generating device to communicate. Implications from the current study regarding device use among children with autism who use

SGDs to communicate will be mentioned. Future research that can be conducted to assist in learning about this population's use of SGDs will also be discussed.

### *Implications of the Complexity of Using Speech Generating Devices*

Because SGD goals have higher success when family needs are considered, there is a need for more collaboration and involvement of the family in regards to school and private therapy goals. Through better communication and collaboration, goals can be generalized into a variety of settings. Involving families in goal-making can lead to parent investment of goals within the home as well as in school or in private therapy.

Device breakdowns may lead to technology abandonment. In order to facilitate smooth transitions for children with autism using SGDs, an implication of device breakdowns is providing the family with an alternative plan in the case of device problems or breakdowns. Because of the characteristics of children with autism, the disturbance in SGD use not only limits the child's communication, but also lowers consistency and increases challenging behavior.

Changes in device use among children with autism utilizing speech generating devices for one year or longer are not documented. The current study did report changes in device use, however. An implication of changes in device use may be the need to conduct longitudinal research to learn more about long-term uses of device use.

Within the complexity of SGDs as tools for communication theme, a possible implication of the current study is the longevity of device use within families and the need for sustainability. An example of this is London's daughter Alice, is about to graduate from high school and enter into a work type setting.

However, her mom makes the comment that just because she is exiting school does not mean that she does not need any more support or services related to her device use. London says she's going to need this device "forever and ever." There is still a lot she needs to learn in how to communicate. Ongoing use of speech generating devices implies a continual need for support and training for daily use. In addition, technology is constantly changing and provides another reason that people using speech generating devices will need support and training.

Another implication for practice is the need for educating both professionals and parents of children with autism how to teach literacy development to this population. Because of the importance of literacy skills to speaking and listening (Hetzroni, 2004) and expressing oneself (Glennen & DeCoste, 1997), it is important to teach literacy skills to children with autism as well. Special educators and related service personnel must be more proactive in developing rich communication abilities through literacy development. This became apparent as Zachary talked about Kennedy's literacy skills and how she can't read out loud to him or read a book. However, Kennedy is making connections with written text. Through education, parents and professionals can learn how to teach literacy skills and what literacy skills may look like for children with autism who use speech generating devices.

Further research should be pursued in the area of literacy attainment for children with autism using speech generating devices. Within the current study, there were very limited accounts of how children with autism who use SGDs engage in literacy or pre-reading skills. This area is important as literacy

attainment allows more opportunities for self-expression and independence (Glennen & DeCoste, 1997), as well as listening, speaking, reading, and writing (Hetzroni, 2004). The use of visual representation within literacy opportunities (Jewitt & Kress, 2003) may also develop literacy skills because many children with autism learn visually.

### *Implications of the Tension among Structured Device Use and Play*

Within the study, tension was found between play and structured times for families with a child with autism using a SGD. Another possible implication for parents and professionals is allowing children with autism to use speech generating devices for play and exploration, as a typical child plays and explores their voice. By allowing play and exploration on speech generating devices, children are allowed chances to independently find words, make connections, and learn. Nadine and Zachary both talked about the importance of exploration within the device for their child and allowing them to independently play, make patterns, and explore on their own. Exploration may be important not only to increase fluency, but also as a self-expression, learning, and practicing things learned.

The area of play and SGDs with children with autism is an important one for future research because of the importance of play not only to child development, but also to the parental bond. How can SGDs be used to facilitate interactions between parent and child? Future research studies should explore play within the home for children with autism using SGDs for a year or longer. There are only a few research studies regarding SGD use in the home for children with autism and there is a gap in the literature regarding what play looks

like with children who have autism using SGDs for one year or longer. What does play at home look like for children with autism using SGDs for one year or longer? How do play interventions affect children with autism using SGDs for one year or longer within the home?

Toys that are motivating to children with autism may be important to increase interest, play, and social interactions within SGD use. A possible implication for parents and professionals is following the child's interests and likes in order to increase skills that children with autism have difficulty with, such as play skills and social interactions. Parents talked about trying to engage their child while using SGDs to communicate which in and of itself, may be difficult due to the fact that the child has autism. The use of motivation may allow children with autism to engage and increase play skills.

Another area that requires future research is how individuality is shown through the use of SGDs for an individual with autism. The current research provided glimpses of the children's personalities through the retelling of stories by the parents, but it is important to find out more about these children's personalities and how they see themselves and how others see them. When Zach talked about his daughter, Kennedy's device use, he said if she said, "Listen to me" on her device, everybody better listen or a tantrum would be next. This is Kennedy's way of not only appropriately communicating and asserting control, but also showing her personality through device use. Understanding more about the children's personalities allows for better device use for communication and educational aspects.

### *Implications of the Interaction of Requests and Social Interactions*

The interplay between requesting and social interaction is complex. Because the ultimate goal is the broad picture of communication, it is important to tease out all of the pieces that are required to facilitate communication with others. The implication of the interplay of requests and social interaction is determining more ways to incorporate social interactions throughout the day that combine communication with interaction. An example of this is an activity Jefferson enjoys that combines requests with interaction. Moira described tickles in relation to her son “that’s one of his most favoritist things is tickles by his father.” Tickles are a perfect example of an activity that requires more than a brief social interaction to receive a toy.

All of the parents talk about their child being motivated by food, drinks, and or movies, along with other items. If these are among the most motivating things the child likes to do, this creates a difficulty in engaging the child in language when he/she is eating, drinking, or watching a movie or TV show for these families. A possible implication for parents and professionals is finding activities, environments, and situations which allow interaction through multiple senses, such as Jefferson’s engagement with tickles. Tickles were something physical that incorporated his senses and allowed him to socially interact while continuing being motivated.

Another area for future research within speech generating devices and autism is a deeper look into the communication and language taught to children with autism using speech generating devices. Out of the numerous ways individuals use language, children with autism using speech generating devices

are typically limited to requesting as a way to motivate the child to communicate and social uses of language (Olive et al., 2007; Son et al., 2006; Trembath et al., 2009). This requires further research and understanding of why this occurs and how to continue to increase language for other, more advanced communicative purposes, such as commenting, asking questions, and social communication.

### *Implications of the Need for Advocacy by Parents*

The participants who volunteered for the current study are all middle-class, educated parents. As advocates for their child, a question and implication for families and professionals in the fields of special education and speech-language pathology arises. How do parents who are not well educated navigate the schools and speech generating devices? People who are not as well-educated may be more reliant on the professionals in the field to assist and educate them on their child's options for communication. In order for professionals to engage in a role of assistance for families who are not well-educated or well-versed, professionals need to obtain knowledge about speech generating devices and most effective ways to approach parents.

SGDs should be a more important priority for professionals working with children who have autism and are nonverbal or have limited communication. Pre-service education for speech pathologist and special educators would allow more professionals to be well-versed and prepared to incorporate a variety of augmentative and alternative communication strategies with children who have limited or no communication. More education for professionals already working in the fields of special education, speech pathology, and related areas is another way to increase education and application of SGDs.



Within the area of autism and SGDs, there are several areas that are in need of research. There is a need to better understand the relationships between training and support, and how that impacts familial factors that influence SGDs. How does the training and support received influence families using a SGD with a child who has autism? Families raising a child with autism already have more stress than other families raising a child with a disability (Gray, 2002), so we need to understand how training and support influence family use of a device with a child who has autism.

### *Implications of the Need for Diverse Support Networks*

Within the super-ordinate theme of building a diverse support network, parental role perceptions may play a role with responsibilities of device use between parents. Zachary's experiences regarding responsibilities with device use between he and his wife were shared, while the other four parents who were married felt that the responsibilities were not shared. Implications of gender differences between roles with the device could be used in regard to teaching and using the device within the home. Further research is needed to determine if mother and father roles in device use are in fact different based on gender. Fathers may have different experiences and perceptions about responsibility of device use within parental roles.

Within this study, five families had a sibling in addition to the child with autism. Two families didn't perceive that SGD use affected the sibling because the sibling also had autism. Siblings' roles were described within three families. Two of these families described a sibling who assisted with device use in some way. How do siblings make sense of their brother or sister and the use of speech

generating devices within the home? What effects if any do SGDs have on the sibling? Future research should examine the experiences and perceptions of siblings among children with autism using speech generating devices to gain an understanding of the roles and perceptions of siblings.

Within the current study, the role of the grandparents was introduced, but not fully explored. Implications for practice include educating and training extended family members, such as grandparents so that they can provide more than encouragement if desired. Future research should look at the roles grandparents play in an attempt to understand the dynamic within the family of a child with autism who uses a speech generating device.

### Summary

The purpose of this study was to investigate family experiences with a child who has autism who uses a speech generating device to communicate. Five super-ordinate themes emerged from the interviews. The complexity of SGDs as tools for communication was the first super-ordinate theme and it allowed an understanding of how SGDs are complex, but can be used in various ways to create an environment for communicating. The second super-ordinate theme of tension between structure and play resonated with how families used the device within structured and play times to create communication opportunities for their child with autism. Next, the super-ordinate theme of the interplay between requesting and social interaction showed clear differences between the uses of the device for requesting something versus socially interacting. The fourth super-ordinate theme that emerged was the fluctuating role of the parent advocate that changed depending on the needs of the child.

The fifth and final super-ordinate theme was the building of diverse support networks in order to continue device use. The study implications focused on the need for sustainability within device use and support and training for families using devices and professionals that work in fields with individuals with autism. Future research should focus on the exploration of roles within the family that are important to device use, along with a better understanding of the relationship between training and support and sustained device use. Other areas that are important to research and understand with device use and autism are how SGDs affect the child's personality and how SGDs can be used to teach literacy skills to children with autism using SGDs.

## APPENDIX A

### INTERVIEW QUESTIONS FOR WEEKLY INTERVIEWS

1. How do you use (child's) device on a typical day?
  - a. Probes may include: can you tell me more about that, you mentioned \_\_\_\_, how does that go? Etc.
2. Can you tell me about your family experiences this week with (child) using his/her device?
  - a. Probes if needed: What have your family experiences been with bedtime, mealtime, playtime, bath time, etc.
3. What have your family experiences been with device use for (child) after school and at night?
4. Can you tell me about experiences this weekend with (child) and his/her device?
  - a. How did that work? Can you tell me a little bit more about that?, etc.
5. Can you tell me about your family experiences with using the device with (child) and (sibling) this week?
6. What have your family experiences been with the technical use of the device?
7. What have your family experiences been with (child) and device use at school?
8. What have your family experiences been with (child) and device use in private therapy?

\*Note—Questions will be open-ended as to allow the participant to lead the conversation. Researcher will ask probing questions (i.e. Can you tell me more about that? How does that work?) throughout based on the information and

language the parent uses. For example, if the parent says, "It is hard." The researcher might ask, "Can you tell me what you mean by *hard*?" This allows space to collect and interpret participants' description of their lived experiences, a primary goal for phenomenological studies.

## APPENDIX B

## IRB FORM



THE UNIVERSITY OF  
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## INSTITUTIONAL REVIEW BOARD

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Phone: 601.266.6820 | Fax: 601.266.4377 | [www.usm.edu/irb](http://www.usm.edu/irb)

## NOTICE OF COMMITTEE ACTION

The project has been reviewed by The University of Southern Mississippi Institutional Review Board in accordance with Federal Drug Administration regulations (21 CFR 26, 111), Department of Health and Human Services (45 CFR Part 46), and university guidelines to ensure adherence to the following criteria:

- The risks to subjects are minimized.
  - The risks to subjects are reasonable in relation to the anticipated benefits.
  - The selection of subjects is equitable.
  - Informed consent is adequate and appropriately documented.
  - Where appropriate, the research plan makes adequate provisions for monitoring the data collected to ensure the safety of the subjects.
  - Where appropriate, there are adequate provisions to protect the privacy of subjects and to maintain the confidentiality of all data.
  - Appropriate additional safeguards have been included to protect vulnerable subjects.
  - Any unanticipated, serious, or continuing problems encountered regarding risks to subjects must be reported immediately, but not later than 10 days following the event. This should be reported to the IRB Office via the "Adverse Effect Report Form".
  - If approved, the maximum period of approval is limited to twelve months.
- Projects that exceed this period must submit an application for renewal or continuation.

PROTOCOL NUMBER: **11111501**

PROJECT TITLE: **Parent Experiences and Children with Autism  
who use Speech Generating Devices**

PROJECT TYPE: **Dissertation**

RESEARCHER/S: **Rebecca Mullican**

COLLEGE/DIVISION: **College of Education & Psychology**

DEPARTMENT: **Curriculum, Instruction, & Special Education**

FUNDING AGENCY: **N/A**

IRB COMMITTEE ACTION: **Expedited Review Approval**

PERIOD OF PROJECT APPROVAL: **12/07/2011 to 12/06/2012**

**Lawrence A. Hosman, Ph.D.**  
**Institutional Review Board Chair**

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